Report on the Delphi Study to Identify Key Questions for Inclusion in the National Patient Experience Questionnaire

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Contents

Executive summary

This document provides a detailed account of the process used to identify the 60 key questions for inclusion in the National Patient Experience (NPE) questionnaire and a further 40 questions ranked for inclusion if required. These questions were drawn from a library of 189 questions provided by Picker Institute Europe. The study was commissioned by the National Patient Experience Programme and overseen by an Advisory and Delivery group.

Methodology

A Delphi methodology was adopted for the implementation of the study. This was particularly useful in achieving consensus across a variety of different stakeholders who are not ordinarily in direct communication with each other. The implementation of the study involved a number of processes and is focused on:

- The creation of a panel of expertise
- Development and implementation of a two-round study
- Quantitative and qualitative analysis of the emerging data
- Integration of findings from focus groups that had been conducted with patients (n=6; 48 participants) and data users (n=2; 14 participants) by personnel from the National Patient Experience Programme prior to the commencement of the Delphi study. These findings were taken into account in the second round of the Delphi study.
- Benchmarking findings from the Delphi study against key criteria, including themes relating to the patient pathway through the health system, concepts of patient experience, the 2012 HIQA standards and the findings from the focus group discussions.

Data collection

The panel of expertise was developed using a combination of a purposive snowball sampling methodology and literature search. In total, 60 participants from a variety of stakeholder groups, including policy-makers, managers, clinicians, patients and data research experts, consented to take part. While the level of expertise varied by thematic area (e.g. "Ambulance service", "Accident & Emergency", "Waiting lists and planned admission"), three-quarters (75%) of participants indicated they had either a very good or excellent level of knowledge about patient experience. A response rate of 97% (n=58) was achieved in the first round and 80% (n=48) in the second round.

The first round questionnaire focused on identifying those questions considered to be the most important to include in the NPE questionnaire. A five-point categorical scale was used with the response categories: 'definitely yes', 'probably yes', 'maybe yes / maybe no',

'probably no', and 'definitely no'. The questionnaire was pre-tested (n=2) and piloted (n=3) and minor changes were made to the layout, information, and wording of some questions. Analysis of the data took place using descriptive statistics.

Findings

A cut-off point of 75% was used in the first round to identify priorities; that is, where 75% or more of the participants on the Delphi panel agreed a question should probably or definitely be included in the NPE questionnaire, it was identified as a priority. Using this approach, 105 questions were identified as priorities. Qualitative analysis took place on information provided by participants in respect of the rationale for why individual questions should not be prioritised and this information was made available in the second round.

Participants were also asked if they thought there were any additional areas that had not been included in the first round. A total of 33 question areas were identified and these ranged from "family and carers" to "patient characteristics" to "services and supports". Questions about each of these areas were included in the second round Delphi and participants were asked to indicate whether they should be included in the NPE questionnaire.

The integration of data from the first round study was compared with the findings from the patient and data user focus groups and this showed a high level of agreement. Out of the overall question library of 189 questions, there were 64 questions that were common to all three groups.

The second round questionnaire provided information on the findings from the focus groups in respect of each individual question and participants were asked to take this information into account in their deliberations. A sliding scale from 0-100 was used in the second round to rate questions to be included in the NPE questionnaire. The availability of continuous data facilitated the use of measures of central tendency (the mean) and dispersion (standard deviation).

At the end of the second round, the top 100 questions were identified using a cut-off point of a mean of 75 or higher. Within this, 35 questions had a mean of 90 or higher suggesting a very high level of consensus around these questions.

Consideration of Delphi findings by theme and in national context

The top 60 prioritised questions from the second round were assessed against the thematic areas outlined in Picker Institute Europe library of questions to determine comprehensiveness. Three areas, "the Ambulance service", "Waiting lists or planned admissions" and the sub-theme of "Visitors" under "Hospital and wards" did not have any questions in the top 60 prioritised. In the top 100 prioritised questions, the "Ambulance service" was identified as having three questions, while "Waiting lists or planned

admissions" and the "Visitors" sub-theme were not identified as having any. In contrast, the theme "Leaving hospital" was identified as having 13 prioritised questions in the top 60. Suggestions about the inclusion of a small number of alternative questions based on their rank as determined by the Delphi panel were made to accommodate these differences.

Some consideration was also given to the concept of patient experience and, similar to the issues arising in respect of the thematic areas, some variation was identified in the extent to which individual areas were prioritised. While 16 questions (27%) relating to the concept "Information, communication and education" were included in the top 60, other areas such as "Demographics", "Access to care", "Emotional support", "Involvement of family and friends" and "Lead-in" questions had only one or two questions on each one. Some consideration was given to how these deficits could be addressed and suggestions for changes presented.

In order to ensure the prioritised questions aligned with the Irish context, benchmarking took place against the relevant area under the HIQA standards. Again, some issues were identified and some standards (e.g. Standard 1.1 *The planning, design and delivery of services are informed by service users' identified needs and preferences*") did not have any prioritised questions in the top 60. A similar situation applied in respect of Standard 2.7 ("*Healthcare is provided in a physical environment which supports the delivery of high quality, safe, reliable care and protects the health and welfare of service users")* where only one question was prioritised, despite 13 questions being available in the library of 189 questions. Twenty-four questions relating to Standard 1.4 ("*Service users are enabled to participate in making informed decisions about their care*") were identified in the top 60 and this accounted for 40% of all questions prioritised.

The final area of deliberation related to the recommendations by patient focus groups to combine or merge some questions. While, in total, 86 questions were identified by between one and six focus groups to be combined with others, only seven of those questions were included in the top 100 prioritised. Each of these questions were considered in detail and issues arising highlighted.

In conclusion, the findings from the Delphi study showed high group agreement as well as consensus with the findings from patient and data user focus groups. Some issues arose in respect of the top 60 and top 100 prioritised questions and, in order to take account of these issues, a small number of changes were suggested. The suggestions made were based on the highest ranked questions selected by the Delphi panel that met the requirements outlined.

 The top 60, and additional 40, questions prioritised by the Delphi panel are presented in Section 9 (page 74-78) of this report.

1.0 Background to the study

There is an increasing recognition that patient experience is an important element of quality and safety in the health services. A recent systematic review of international research reported consistent evidence of a positive association between patient experience and patient safety and clinical effectiveness across a wide range of settings, population groups, outcome measures and disease areas (Doyle, et al., 2013). The implementation of patient experience surveys is now well-established across different jurisdictions (Jenkinson, et al., 2002) and are increasingly used to inform service provision at local (Graham, et al., 2015) and national level (Sanders, et al., 2015). The importance of patient experience has also been acknowledged in the Irish context and a commitment made to measure and understand the experiences of patients who access hospital care.

Extensive work has taken place in developing questions for inclusion in patient experience survey and a library of 189 questions were provided by Picker Institute Europe, which is an international charity working since 2000 across social and health care. Each of the 189 questions have a focus on areas relevant to patient experience and each has been previously tested and validated internationally. The selection of key questions, from this library, for inclusion in a patient experience questionnaire forms the focus for this study.

The study is based on a Delphi methodology which is a research approach used to gain consensus through a series of rounds of questionnaire surveys, usually two or three, where information and results are fed back to panel members between each round. It is a particularly useful approach in situations where a problem can benefit from subjective judgements on a collective basis, where relevant specialists are not in direct contact with each other, where the number of specialists involved is too large to effectively interact in a face-to-face exchange and where ethical or social dilemmas dominate economic or technical ones (Hanafin and Brooks, 2005).

The Department of Health (DoH), the Health Information and Quality Authority (HIQA) and the Health Service Executive (HSE) have adopted a partnership approach to develop a model and methodology and implement a National Patient Experience Survey Programme in Ireland. This type of approach has been adopted as it will provide all partnership organisations with the opportunity to have greater engagement with patients, to hear the patient's voice and, therefore, to use the patient's experience to drive quality and safety of care within the remit of their organisations. The partnership organisations are currently developing the model and methodology to implement the National Patient Experience Survey Programme. This includes:

1. the purchase a library of 189 questions for the survey tool and to adapt or adopt those questions for the Irish healthcare system;

2. commissioning the distribution of the survey and website that will facilitate this programme; and
3. development of a communications plan to inform and engage with patients;

1.1 Structure of the 189 questions

The 189 questions incorporate a number of different thematic areas related to the patient journey and are presented under the themes presented in Figure 1.

Figure 1: Themes which frame the questions

- A. Admission to hospital (39 questions)
- B. The hospital and ward (42 questions)
- C. Doctors (9 questions)
- D. Nurses (8 questions)
- E. Your care and treatment (32 questions)
- F. Operations and procedures (9 questions)
- G. Leaving hospital (28 questions)
- H. Overall (8 questions)
- I. About you (11 questions)
- J. Other comments (3 questions)
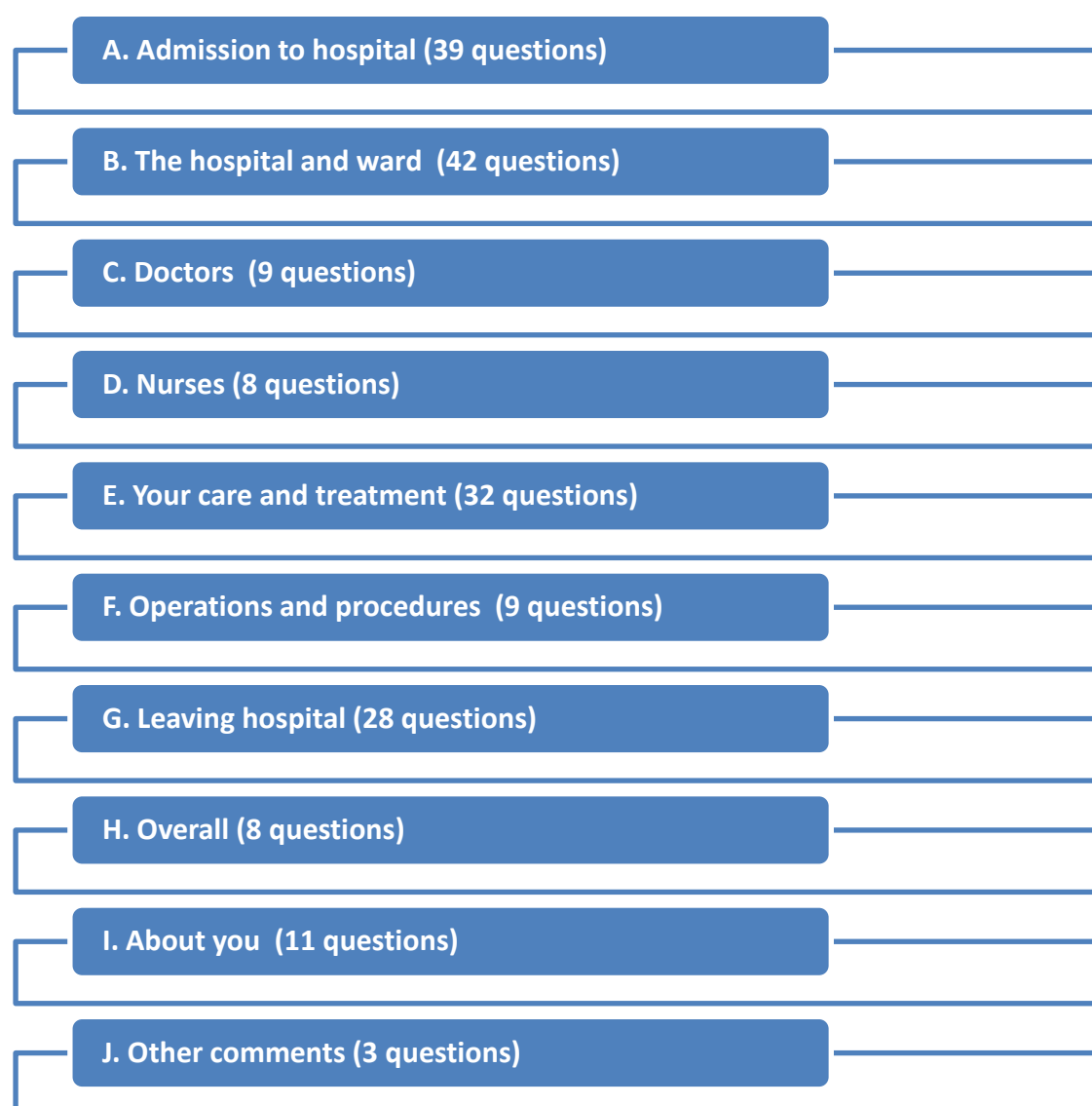
Some of the themes outlined in Figure 1 incorporate sub-themes. For example, the theme "Admission to hospital" includes four sub-themes ("Emergency care", "The accident and emergency department", "Waiting list or planned admission", "All types of admission").

"The Hospital and ward" theme includes two sub-themes (Visitors and Food) and the theme "Your care and treatment" includes three sub-themes (Pain, Tests, and Treatments).

1.2 Conceptualisation of patient experience

The term "patient experience" has been used in healthcare practice for many years and there is an increasing focus on achieving a common definition and understanding of the concept since this will determine how it is measured (Wolf, et al., 2015). There is some agreement that patient experience is not the same as patient satisfaction and authors have highlighted the complex relationship between patient satisfaction and expectations of care (Shale, 2013), which is, in turn, influenced by the diversity of the patient (culture, age, and conditions) and may be affected by previous experiences of services and / or care (Sanders, et al., 2015). There is some agreement that patient experience includes patient satisfaction but that it goes beyond this to take account to the actual care experienced. This is highlighted in the review by Wolf et al. (2015) who identified 18 sources that provide a variety of definitions of patient experience. These definitions incorporate a range of divergent views by different authors within the health care sector. Examples presented include:

- "*Health system responsiveness which specifically refers to the manner and environment in which people are treated when they seek healthcare*" (Bleich, et al., 2009)
- "*Patients' self-reports of their experience of inpatient care, including staff-patient interactions, information provision, involvement in decision and support for self-care and overall ratings of care*" (Hewitson, et al., 2014)
- "*The sum of all interactions, shaped by an organisation's culture, that influence patient perceptions, across the continuum of care*" (The Beryl Institute, 2016)

These definitions were discussed with both the Advisory and Delivery Group for the Study and it was determined that the definition presented by the Beryl Institute (2016) was the most appropriate one for this study. This definition provides a comprehensive approach to patient experience by taking account of multiple interactions, organisational culture, patient perceptions and the continuum of care

Domains

While definitions of patient experience vary, there is some agreement about core areas to be measured and a number of recent reviews have been conducted (Fitzpatrick, et al., 2014; Sanders, et al., 2015; Graham, et al., 2015). The original Picker adult in-patient questionnaire (Jenkinson, et al., 2002) identified the following dimensions of patient experience:

1. Information and education
2. Co-ordination of care

3. Physical comfort
4. Emotional support
5. Respect for patient preferences
6. Involvement of family and friends
7. Continuity and transition

More recently, Picker Institute Europe in association with the University of Oxford conducted a study to develop a simple, conceptually grounded and unified model for assessing patient experience and to evaluate that model. The authors (Fitzpatrick, et al., 2014; p26) noted that they choose the NHS Patient Experience Framework as a working definition for use as:

The NHS Patient Experience Framework is based on the Picker Institute's Principles of Patient-Centred Care and includes the following eight domains:

1. **Respect for patient-centred values, preferences, and expressed needs,** including: cultural issues; the dignity, privacy and independence of patients and service users; an awareness of quality-of-life issues; and shared decision making;
2. **Co-ordination and integration of care** across the health and social care system**;**
3. **Information, communication and education** on clinical status, progress, prognosis, and processes of care in order to facilitate autonomy, self-care and health promotion;
4. **Physical comfort** including pain management, help with activities of daily living, and clean and comfortable surroundings;
5. **Emotional support and alleviation of fear and anxiety** about such issues as clinical status, prognosis, and the impact of illness on patients, their families and their finances;
6. **Welcoming the involvement of family and friends**, on whom patients and service users rely, in decision-making and demonstrating awareness and accommodation of their needs as caregivers;
7. **Transition and continuity** as regards information that will help patients care for themselves away from a clinical setting and co-ordination, planning and support to ease transitions;
8. **Access to care with attention,** for example, to time spent waiting for admission or time between admission and placement in a room in an in-patient setting, and waiting time for an appointment or visit in the out-patient, primary care or social care setting.

These concepts are coherent with elements outlined in the National Standards for Better Safer Healthcare, particularly those relevant to person-centred care (Health Information & Quality Authority, 2012).

1.3 Developments prior to the implementation of the Delphi study

The patient's voice is essential to inform quality improvement initiatives at a local and national level. As a starting point in identifying the most important aspects of the NPE

questions for inclusion in the Irish context, focus groups were conducted by the National Patient Experience Survey Programme to ensure the voice of patients and data users were heard. Eight focus groups were conducted with patients (n=6 focus groups; 48 participants) and data users (n=2; 14 participants). The focus groups were two hours in length and conducted over a three-week period between 26 May 2016 and 10 June 2016.

There were three main aims:

1. To ensure that the Frequently Asked Questions (FAQ) is easily understood and answers all potential questions.
2. To explore possible survey distribution methods, that is by email, post or text.
3. To review and refine the library of 189 survey questions.

The focus group provided a forum to allow the participants to review the library of 189 survey questions and to give their feedback on each one. Focus groups have a set structure with a facilitator(s) who is responsible for chairing and asking the questions, a scribe who writes the notes and, for larger groups, the raconteur who feeds back on findings for each group. In these focus groups, opinions were received on each of the 189 individual questions and recommendations were made about whether the question should be included, excluded or combined with another question. This data has been integrated at a granular level into the Delphi process so that members of the Delphi panel were able to take them into account in their deliberations.

A full report on the findings from the patient focus group interviews is available at the HIQA website (http://www.patientexperience.ie/).

Summary

The background to this study takes account of the increasing national and international focus on measuring patient experience. While there is not a consensus on the definition of patient experience, there is considerable overlap in the broad concepts underpinning it and these concepts have been considered in some detail by Picker Institute Europe. A library of 189 questions were purchased from Picker Institute Europe and these questions were considered in some detail prior to the commencement of this study by patients and data users using a focus group methodology. The integration of these views into the Delphi study form a key focus for this report.

2.0 Governance of the study

A governance structure to oversee the implementation of the Patient Experience Survey is in place with two main structures overseeing it: an Advisory Group and a Delivery Group. These structures provided guidance for the implementation of the Delphi Study.

2.1 Advisory Group

The National Patient Experience Advisory Group provides input and advice as to the most appropriate scope, model and outputs for a National Patient Experience survey, with a focus on all patients who have stayed a minimum of one night in public acute care. The National Patient Experience Advisory Group is chaired by the HIQA and comprised of representatives from: the DOH; HIQA; HSE; a patient representative; clinical care, in particular, an acute care representative; and subject and academic experts.

Terms of Reference

The role of the National Patient Experience Advisory Group is to provide:

1. Advice on the National Patient Experience Survey model
2. Advice on the themes for the survey that will provide an accurate reflection of the inpatient acute care experience
3. Advice on the questions and whether appropriate or otherwise
4. Advice on requirements for the survey tool and website
5. Provide advice in respect of the development of new processes, procedures, tools and functions to ensure the survey is effectively implemented
6. Advice on methodology to implement the NPE survey for example sample size
7. Advice on the most effective communication strategy
8. Advice on appropriate national outputs, to ensure that the patient, service providers and public are fully informed of the findings from the NPE survey
9. Review and advise on learning from NPE survey.

2.2 Delivery Group

The National Patient Experience Delivery Group is responsible for developing and implementing the model and methodology for the National Patient Experience Survey Programme. They provide leadership ensuring the agreed timelines and outputs are achieved for each of the partner organisations. The Delivery Group is chaired by the HIQA and comprises representatives from: the DOH; HIQA; and HSE.

Terms of reference

The Terms of Reference for the National Patient Experience Delivery Group are as follows:

1. Assist with protection of survey scope to ensure programme remains aligned to National Inpatient Acute Care Sector
2. Plan, co-ordinate and conduct focus groups to adapt international question set for Ireland's survey model
3. Prepare and propose options for survey model and methodology to Advisory Group
4. Prepare and present reports advising steering group of programme progress
5. Assist with programme to cognitively test survey tool
6. Assist with co-ordination of Delphi consultation
7. Contribute as necessary to Privacy Threshold Assessment and, if necessary, a Privacy Impact Assessment
8. Identify processes and procedures within own organisations that can inform and assist with process development
9. Provide input and assistance with: the compilation of business requirements development of Tender for third party software and website developer; and conducting assessment and awarding contract
10. Assist with development of processes, procedures, guidance, tools, and functions to ensure the survey is appropriately managed
11. Contribute towards development and implementation of communication strategy
12. Drive and provide stakeholder engagement promoting the programme within own organisation and across healthcare sector
13. Assist with development of Patient Experience Survey Programme outputs, to ensure that the patient, service providers, partners and public are fully informed of the findings from the NPE survey
14. Provide advice and assistance to ensure results are appropriately analysed and distributed
15. Assist with management and delivery of close out session
16. Review and advance National Patient Experience Survey Programme as required throughout the programme.

Presentations were made in the course of the Delphi study to both groups and advice sought and received on a number of key areas relevant to the study implementation.

The following section presents the methodology used in the implementation of the Delphi study undertaken to reduce the number of questions from 189 to 100.

3.0 Methodology

The Delphi technique is a research approach used to gain consensus through a series of rounds of questionnaire surveys, usually two or three, where information and results are fed back to panel members between each round. This methodology facilitates the co-construction of knowledge by participants. It does this by enabling a process of individual feedback about group opinion, with opportunities for respondents to change their position, primarily on the basis of that feedback. In this study, participants were able to take account of the views emerging from focus groups with data users (n = 2) and patients (n = 6) in addition to the feedback from other panel members. A Classical Delphi Technique was adopted and this has five characteristics: anonymity, iteration, controlled feedback, statistical group response and stability among responses.

The use of a Delphi methodology is particularly useful in situations where:

- a problem does not permit the application of precise analytical techniques but can benefit from subjective judgements on a collective basis;
- where the relevant specialists are in different fields and occupations and not in direct communication;
- where the number of specialists is too large to effectively interact in a face-to-face exchange and too little time are available to organise group meetings; and
- where ethical or social dilemmas dominate economic or technical ones (Hanafin & Brooks, 2005).

In this study, the approach used was particularly helpful in enabling participants to take account of the views of data users and patients who had taken part in focus group discussions prior to the commencement of the Delphi study.

3.1 Purpose of this Delphi study

The purpose of this Delphi study is:

> to refine the library of 189 international questions to a core of 60 questions with an additional 40 questions to be chosen (in a ranked order) to allow for the option to add more questions to the survey tool.

Objectives

The objectives of this study are to:

1. reach consensus about the questions to be included in a NPE questionnaire that reflect the views of key stakeholders;

2. achieve a NPE questionnaire that adequately reflects patient experiences in the Irish context

3. consider findings of the Delphi process in terms of concepts of patient experience, the overall balance of themes covered and all stakeholder views.

3.2 Processes involved in the implementation of this study

An overview of the processes undertaken in the implementation of this Delphi study are set out in Figure 2.

Figure 2: Processes involved in the implementation of the Delphi study

Creation of panel of expertise

- Identification of a sampling frame
- Identification of relevant individuals
- Preparation of relevant material to inform potential participants
- Issue of invitation to take part in Delphi study
- Agreement to take part

Round 1: Preparation and implementation

- Preparation of relevant material
- Development of Round 1 instrument to include pre-determined questions, rating scale, additional areas required and criteria for inclusion
- Pre-testing Round 1 instrument
- Issue questionnaire to participants using on-line approach
- Collate responses and issue reminders if required
- Analysis of information from Round 1 using descriptive statistics and qualitative thematic analysis to identify key issues arising
- Identification of level of consensus and other issues arising

Round 2: Preparation and implementation

- Preparation of relevant material
- Development of Round 2 instrument to take account of the findings from the analysis of Round 1 material
- Inclusion of the findings from patient and data user focus groups by individual question
- Issue questionnaire to participants using on-line approach
- Collate responses and issue reminders if required
- Analysis of information from Round 2 using descriptive statistics such as the mean and standard deviation and thematic analysis
- Identification of level of consensus.

Benchmarking against criteria for patient experience

- Benchmark overall findings against criteria for conceptualising patient experience (validity) and questionnaire reliability
- Benchmark findings against issues identified from focus groups
- Benchmark findings against the HIQA standards for better healthcare

Report

- Draft report on study
- Identify the 60 core questions to be included in an instrument
- Identify additional 40 questions

3.3 Panel of expertise

Delphi's claim to credibility lies in its ability to draw on expertise and this is promoted by purposeful selection of 'experts' for inclusion to the panel rather than relying on random sampling. In this study we refer to a "panel of expertise" rather than a "panel of experts" since the term "expert" is highly contested. There is no standard approach to identifying a panel of expertise to take part in a Delphi study and various mechanisms are used. A systematic review on using, and reporting, the Delphi method (Boulkedid, et al., 2011) identified a number of different approaches to selecting participants for inclusion on the panel, including: "willingness to take part", "renown", "membership of an organisation", "recommendation", "years of experience", "random", "interest in area", "geographical location", and "specific criterion", such as age, language or knowledge.

In this Delphi study some consideration was given to identification of panel members and areas taken into account included a need for:

- expertise in measurement;
- expertise in patient experience across a range of areas;
- expertise in utilising data for decision-making;
- people willing and able to take part; and
- a heterogeneous panel with individuals who come from different stakeholder perspectives.

Following deliberations, a purposive snowball sampling approach was agreed with the NPE Delivery Group and the NPE Advisory group as the most appropriate mechanism for ensuring a wide range of stakeholders with varying types of expertise were included. Five broad stakeholder views were identified as important for inclusion in the panel of expertise and these were:

1. Policy-makers
2. Managers
3. Clinicians
4. Patients
5. Personnel involved in data / Researchers

Information about how these individuals were identified is now provided.

Purposive snowball sampling

A purposive sample is a non-representative subset of some larger population, constructed to service a very specific need. Snowball sampling is a subset of this approach. Snowball sampling is achieved by asking a participant to suggest someone else who might be willing or appropriate for the study. Members of the Delivery Group and the Advisory Group are

drawn from the DOH, HIQA, the HSE, the Central Statistics Office (CSO) and patient representative organisations. Each of these members have been engaged in the development of the process to implement a NPE survey and they hold considerable knowledge and expertise about the area. These members, who are mainly from a managerial and policy-making perspective, were asked to identify and recommend additional individuals across different stakeholder groups, who were known to them to have expertise in the area of patient experience. The involvement of clinicians formed a particular focus for these recommendations.

In addition, patients who had taken part in the focus group discussions were identified as bringing an important perspective and two participants from each group were invited to become panel members. These invitations were issued through the Patient Liaison Officers at the individual hospitals.

Finally, a search of the relevant peer-review databases (e.g. Pubmed, Cinahl, and Medline) was conducted to identify individuals based in Ireland who have published peer-reviewed papers in the area of patient experience. This was informed by a facet analysis which involved breaking down the question "*What authors in Ireland have published research about measuring patient experience*" in to component parts and choosing appropriate terminology to express those parts. Based on this approach a search strategy was developed and implemented. This approach identified a total of 16 individuals across 18 papers. Four papers, however, were co-authored by multiple authors and these individuals were excluded as none were either first or second author on the paper. In total, 14 individuals were invited and 3 consented to take part.

While it is possible to create a number of different panels, in this case, a single panel that included all stakeholders was included. This allowed for a comprehensive approach that enabled consensus to be achieved in the full knowledge of all participants. Specifically, by creating a single panel each member contributed to, and had knowledge of, the views of all other participants.

Figure 3: Participants in the Delphi panel by Round

18
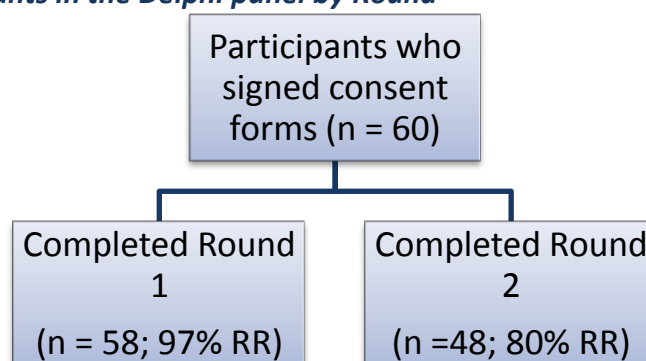
Stakeholders included on the panel

Members of the panel of expertise were drawn from different stakeholder areas (Table 1). The largest group were managers accounting for just over one-third of all stakeholders in Round 1 (n=20; 34%). This was followed by patients (n=12; 20%) who accounted for one in five of those who took part in Round 1. Ten policy-makers (17%), seven clinicians (12%) and six researchers / data experts (10%) took part in Round 1. Three individuals did not state which stakeholder group they belonged to. A similar pattern was identified in Round 2 among the 48 participants who responded, although about 25% did not state their stakeholder group.

Table 1: Number of participants on panel according to stakeholder group

Stakeholder	Number responding Round 1	Number responding Round 2
Clinician	7	3
Manager	20	13
Patient	12	9
Policy-maker	10	5
Researcher / Data expert	6	6
Not stated /other	3	12
Grand Total	**58**	**48**

Participant level of expertise

Panel members were also asked to provide information about their level of expertise. This was done in two ways. In the first part of the questionnaire, individuals were asked "How would you rate your knowledge of patient experience?" The vast majority rated their knowledge as either very good (n=26; 49%) or excellent (n=14; 24%). A further 25% (n=15) rated their knowledge as good and the remaining 4 (7%) rated their knowledge as fair (Figure 4).

Figure 4: Self-rated knowledge by number of Delphi study participants
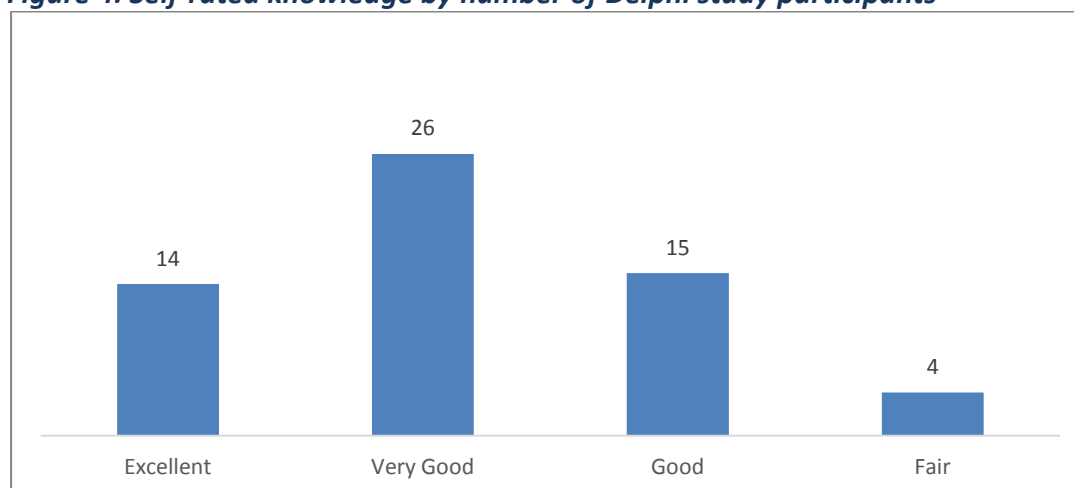
In addition to rating their overall knowledge about patient experience, participants were asked to indicate, at the beginning of each theme, whether they had sufficient expertise to answer questions about the area to make a judgement about whether questions (about the specific section, e.g. "Admission to hospital", "The hospital and ward", etc.) should be included in a national survey on patient experience. It was also stated that if they answered "no" to this question, they would be automatically taken to the following section. This ensured participants on the panel provided a view only on those areas where they felt they had sufficient expertise.

The numbers of individuals who indicated they had sufficient expertise ranged from 41-51 depending on the individual section. The highest percentage (88%) indicated they had sufficient expertise to make a judgement about questions relating to "Admission to hospital", while the lowest number (n=41; 71%) indicated this in respect of "Your care and treatment" (Table 2).

Table 2: Level of expertise by individual section

Section	Number	Percentage
Admission to hospital	51	88%
The hospital and ward	47	81%
Doctors	47	81%
Nurses	47	81%
Operations and procedures	47	81%
Your care and treatment	41	71%
Leaving hospital	44	76%
Overall	44	76%

3.4 Round 1: Questionnaire development and implementation

The development of the first round questionnaire took account of best practices in the area (Robson, 1993, Punch, 1998, Cohen, et al. 2000) and consideration was given to:

- question content;
- question wording;
- form of response to the question; and
- place of the question in the sequence.

The questionnaire was structured around the library of survey questions presented by themes as outlined earlier. Provision was made for commentary under each section and also at the end of the questionnaire. Initially, a nine-point Likert scale was identified as a response to whether individual questions were sufficiently relevant to include in the NPE questionnaire. Following discussion with the Advisory Group, a five-point categorical scale was adopted. Specifically, participants on the Delphi panel were asked to consider each individual question and make a judgement about whether that question was sufficiently

important to be included in the NPE survey. The following options with explanations were presented:

- **Definitely yes:** if you believe this question is essential to include in a national survey about patient experience
- **Probably yes:** if you think the question is a high priority but not essential for inclusion in a national patient experience survey
- **Maybe yes/maybe no:** if you think the question is a medium level priority for inclusion in a national patient experience survey
- **Probably no:** If you think the question is a low priority for inclusion in a national patient experience survey
- **Definitely no:** If you think the question is not a priority at all for inclusion in a national patient experience survey

Pilot testing

While pilot testing in Delphi studies is optional, it is useful to identify ambiguities and improve the feasibility of administration (Powell, 2003). In view of the importance of the study to future health service developments, both pre-testing and piloting took place prior to both questionnaire rounds. The main changes in the first round related to:

- changes to the layout of the questionnaire;
- changes to the information provided; and
- question wording changes.

The pilot test also provided an opportunity to estimate the length of time for completion and this, along with the changes outlined, ensured the questionnaire was feasible for busy stakeholders to answer.

Data collection and response rate

The questionnaire was made available online using SurveyMonkey©. While provision was also made for completion in hard copy, no participant requested this. In keeping with good practices in the area, participants on the Delphi panel were provided with explicit instructions on how to complete the questionnaire, as well as contact details for assistance in case of any difficulties. Three broad strategies were used to ensure high response rates and these were:

1. a cover letter sent by email, on behalf of the Director of the Health Information Directorate, HIQA, to each participant highlighting the importance of taking part in the study;
2. an email reminder sent 48 hours before the completion date for the first round asking participants to complete the questionnaire as soon as possible; and

3. direct contact by members of the NPE Delivery Group with individual participants which greatly enhanced completion rates.

This resulted in a 97% completion rate for Round 1.

Data analysis: Round 1

Analysis that takes place in a Delphi study has two purposes. First, analysis is required to provide feedback between rounds for respondents and, second, it must be able to identify when consensus has been reached. There is not agreement about the best method of measuring this and both quantitative and qualitative techniques have been used. Consideration was given to the most appropriate analytic technique to be applied in the first round questionnaire. The use of a categorical scale in the first round questionnaire allowed for the identification of questions based on the percentage who indicated a question should "probably be included" or "definitely be included". In a review of consensus measurement in Delphi studies, Von der Gracht (2012) reported varying cut-off levels ranging from 51% - 80% and it is clear that there is no single cut off point. A cut off point of 75%, was used in this study as it is in line with findings from Von der Gracht's review and, in addition, it facilitated the identification of approximately 100 questions for inclusion. All questions where 75% or more of the participants agreed the question should "probably" or "definitely" be included were identified. In total, 105 questions from the original questions were identified by adopting this level of consensus (See section on Findings: 1st Round).

In addition, qualitative data in respect of individual sections was compiled and this information was made available in the second round for individual questions. The qualitative data focused on questions that participants indicated should not be included in the final NPE questionnaire.

A question was included at the end of the first round questionnaire on any additional areas individuals felt need to be developed and this data were collated and the findings also presented in the Round 2 questionnaire.

3.5 Round 2: Questionnaire development and implementation

In keeping with the Delphi technique, the findings from the preliminary analysis of Round 1 were incorporated into the Round 2 questionnaire. Due to the importance of ensuring the findings from the focus groups were taken into account, the findings from all three sources were presented in respect of each question included in the Round 2 questionnaire. An example of how this was presented to Delphi panel participants is illustrated in Figure 5.

Figure 5: Example of how each individual question was presented in Round 2

As illustrated, a sliding scale from 0-100 was used in this round to ensure sufficient variability in the final set of questions, thus allowing a ranking process to take place. In addition, at the beginning of each section, qualitative data was presented in a separate document which could be accessed by participants taking part. This provided the rationale given by panel members in the first round for the exclusion of individual questions.

Data analysis: Round 2

The analysis of the second and final round data was mainly quantitative, although some qualitative analysis also took place. The use of a sliding scale provided continuous data and this facilitated the use of the mean, which as a measure of central tendency can be understood as representing group opinion of those questions. The standard deviation was also calculated for each question and as this is a measure of spread it can be understood as a representation of the amount of disagreement within the panel. Where the standard deviation is low, then the panel is in agreement. The converse s also true; if the standard deviation is high, the panel is in disagreement.

In this round, the standard deviation ranged from a low of 7.76 to a high of 30.64 in the top 100 questions selected. Individual questions were ranked on the basis of the mean; those with the highest mean were ranked as the highest. Consideration was given to the standard deviation in the overall context of questionnaire validity and the findings on this are presented in the Round 2 results section.

3.6 Ethical issues

Ethical issues were given due consideration throughout the process and the study actively subscribed to principles of mutual respect, non-coercion and non-manipulation. The potential for harm in the study was low because participants were mature adults, and as each were chosen on the basis of their expertise, they could not be considered as

vulnerable. Key issues around consent, privacy and confidentiality of data were considered at each stage.

A signed consent form was completed by each participant and the following areas agreed:

- the participant had read and understood the attached *Participant Information Leaflet* for this study;
- the participant had the opportunity to ask questions and discuss the study;
- the participant received satisfactory answers to all questions, where he / she had a query;
- the participant received enough information about this study;
- the participant understood he / she was free to withdraw from the study at any time until the closing date for each questionnaire round;
- the participant understood anonymised data will be archived for future research; and
- the participant explicitly agreed to take part in the study.

Privacy issues can be violated during the course of a study such as this and confidentiality and anonymity must be to the forefront of decisions taken. Confidentiality implies that research data which includes identifiable information on participants is not to be disclosed to others without the explicit consent of the participants. In this study, only the minimum amount of personal data required was sought and personal data was not used for any purpose other than that specified at the time of the collection. All data was anonymised and all research outputs, including feedback between Round 1 and Round 2, were checked carefully to ensure no individual was identifiable.

All appropriate steps were taken to ensure both quantitative and qualitative data were held in a secure way. This included the removal of direct identifiers and the use of technical means to break the link between data and identifiable individuals. Both system and physical security safeguards were put in place to ensure the data were protected.

In summary, this section has described in detail the methods used in this Delphi study. Key methodological issues relating to the Delphi methodology have been considered and data presented about stakeholders, panel of expertise, data collection, questionnaire development, data analysis and ethical issues arising.

4.0 Findings: Round 1

This section presents the findings from Round 1 of the Delphi study. In this round, a panel of 58 participants, comprising patients / patient representatives, clinicians, policy-makers, managers and research / data experts took part and a 95% response rate was achieved. The three-part questionnaire asked participants to:

1. provide basic demographic data about themselves;
2. rate the individual questions according to whether they should be included or excluded; and
3. to comment on whether there were additional questions that should be included and their overall comments on the questions.

4.1 Round 1: Questions prioritised for inclusion in the NPE questionnaire

The overall findings (Table 3) show a high level of consensus around the questions that should "definitely" or "probably" be included. A consensus level of 75% was applied and the prioritised individual questions are ranked in Table 3 on the basis that 75% or more participants indicated that the question should either "definitely" or "probably" be included. In total, 105 questions met the 75% inclusion criteria. Between 90% and 100% (n=43; 41%) of participants indicated that 40% of those questions "probably" or "definitely" should be included and two questions (Q139 and Q197) were identified by all participants.

Table 3: Questions prioritised by participants in Round 1 for inclusion in NPE questionnaire

Question number	Question	% indicating inclusion
Q139	After the operation or procedure, did a member of staff explain how the operation or procedure had gone in a way you could understand?	100%
Q197	Was there anything that could be improved?	100%
Q51	Were you given enough privacy while you were on the ward?	98%
Q62	Did the staff treating and examining you introduce themselves?	98%
Q103	Was your diagnosis explained to you in a way that you could understand?	98%
Q110	Were you given enough privacy when being examined or treated?	98%
Q48	When you needed help from staff getting to the bathroom or toilet, did you get it in time?	96%
Q83	When you had important questions to ask a doctor, did you get answers that you could understand?	96%
Q100	Were you involved as much as you wanted to be in decisions about your care and treatment?	96%

Question number	Question	% indicating inclusion
Q117	Do you think the hospital staff did everything they could to help control your pain?	96%
Q127	Did you feel you could refuse any treatment that you did not agree with or did not want?	96%
Q132	Beforehand, did a member of staff explain the risks and benefits of the operation or procedure in a way you could understand?	96%
Q140	Did you feel you were involved in decisions about your discharge from hospital?	96%
Q149	Before you left hospital, did the doctors and nurses spend enough time explaining about your health and care after you arrive home?	96%
Q151	Did a member of staff explain the purpose of the medicines you were to take at home in a way you could understand?	96%
Q159	Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	96%
Q196	Was there anything particularly good about your hospital care?	96%
Q109	Were you given enough privacy when discussing your condition or treatment?	94%
Q124	Did a doctor or nurse explain the results of the tests in a way that you could understand?	94%
Q125	Before you received any treatments (e.g. an injection, dressing, physiotherapy) did a member of staff explain what would happen?	94%
Q141	Were you given enough notice about when you were going to be discharged?	94%
Q155	Did a member of staff tell you about any danger signals you should watch for after you went home?	94%
Q168	Overall, did you feel you were treated with respect and dignity while you were in the hospital?	94%
Q135	Beforehand, were you told how you could expect to feel after you had the operation or procedure?	93%
Q85	Did you feel you had enough time to discuss your care and treatment with a doctor?	92%
Q91	When you had important questions to ask a nurse, did you get answers that you could understand?	92%
Q97	How would you rate the courtesy of your nurses?	92%
Q104	If your family or someone else close to you wanted to talk to a doctor, did they have enough opportunity to do so?	92%
Q153	Were you told how to take your medication in a way you could understand?	92%
Q157	Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you?	92%
Q170	Overall... (Please rate)	92%
Q198	Any other comments?	92%
Q134	Beforehand, did a member of staff answer your questions about the operation or procedure in a way you could understand?	91%

Question number	Question	% indicating inclusion
Q136	Did you have enough time to discuss your operation or procedure with the consultant?	91%
Q138	Before the operation or procedure, did the anaesthetist or another member of staff explain how he or she would put you to sleep or control your pain in a way you could understand?	91%
Q21	Overall, did you feel you were treated with respect and dignity while you were in the A&E Department?	90%
Q39	How would you rate the courtesy of the staff who admitted you?	90%
Q47	When you needed to use a toilet or bathroom, was there a suitable one located close by?	90%
Q56	In your opinion, how clean was the hospital room or ward that you were in?	90%
Q70	How would you rate the hospital food?	90%
Q96	If you ever needed to talk to a nurse, did you get the opportunity to do so?	90%
Q150	Before you left hospital, were you given any written or printed information about what you should or should not do after leaving hospital?	90%
Q169	Overall, were you treated with kindness and understanding while you were in the hospital?	90%
Q131	During your stay in hospital, did you have an operation or procedure?	89%
Q12	Were you given enough privacy when being examined or treated in the A&E Department?	88%
Q77	Was the hospital food suitable for your dietary needs?	88%
Q82	Was there one doctor in overall charge of your care?	88%
Q88	If you ever needed to talk to a doctor, did you get the opportunity to do so?	88%
Q89	How would you rate the courtesy of your doctors?	88%
Q93	Did you have confidence and trust in the nurses treating you?	88%
Q126	Before you received any treatments (e.g. an injection, dressing, physiotherapy) did a member of staff explain any risks and/or benefits in a way you could understand?	88%
Q152	Did a member of staff tell you about medication side effects to watch for when you went home?	88%
Q158	Did hospital staff tell you when you could resume your usual activities, such as when to go back to work or drive a car?	88%
Q161	Did hospital staff discuss with you whether you may need any further health or social care services after leaving hospital? (e.g. services from a GP, physiotherapist or community nurse, or assistance from social services or the voluntary sector).	88%
Q162	Do you feel that you received enough information from the hospital on how to manage your condition after your discharge?	88%
Q173	Did you want to complain about the care you received in hospital?	88%

Question number	Question	% indicating inclusion
Q67	Were your visitors given enough information about visiting (e.g. visiting hours and rules)?	87%
Q133	Beforehand, did a member of staff explain what would be done during the operation or procedure?	87%
Q80	Did you get enough help from staff to eat your meals?	86%
Q92	If you had any worries or fears about your condition or treatment, did a nurse discuss them with you?	86%
Q102	While you were in hospital, were you told your diagnosis (explanation of what was wrong with you)?	86%
Q160	Did hospital staff discuss with you whether you would need any additional equipment in your home, or any adaptations made to your home, after leaving hospital?	86%
Q13	When you had important questions to ask doctors and nurses in the A&E Department, did you get answers that you could understand?	85%
Q72	Was there healthy food on the hospital menu?	84%
Q74	Were you offered a choice of food?	84%
Q84	If you had any worries or fears about your condition or treatment, did a doctor discuss them with you?	84%
Q106	Do you feel you got enough emotional support from hospital staff during your stay	84%
Q121	Were you told in advance when your tests, x-rays or scans were going to take place?	84%
Q122	Were your scheduled tests, x-rays or scans performed on time?	84%
Q142	Were your family or someone close to you given enough notice about your discharge?	84%
Q156	Did hospital staff take your family or home situation into account when planning your discharge?	84%
Q57	How clean were the toilets and bathrooms that you used in hospital?	83%
Q60	Did you have somewhere to keep your personal belongings whilst on the ward?	83%
Q68	Were hand-wash gels available for patients and visitors to use?	83%
Q154	Were you given clear written or printed information about your medicines?	83%
Q79	Were you offered a replacement meal at another time?	82%
Q81	How would you rate the courtesy of the catering staff?	82%
Q86	Did you have confidence and trust in the doctors treating you?	82%
Q123	Did a member of staff explain why the scheduled tests were not performed on time?	82%
Q11	While you were in the A&E Department, how much information about your condition or treatment was given to you?	81%
Q36	How organised was the admission process?	81%
Q37	From the time you arrived at the hospital, did you feel that you had to wait a long time to get to a bed on a ward?	81%

Question number	Question	% indicating inclusion
Q61	Did staff wear name badges?	80%
Q98	In your opinion, did the nurses who treated you know enough about your condition or treatment?	80%
Q172	Did you see, or were you given, any information explaining how to complain to the hospital about the care you received?	80%
Q16	While you were in the A&E Department, did a doctor or nurse explain your condition and treatment in a way you could understand?	79%
Q28	In your opinion, had the specialist you saw in hospital been given all of the necessary information about your condition or illness from the person who referred you?	79%
Q143	On the day you left hospital, was your discharge delayed for any reason?	79%
Q19	In your opinion, how clean was the A&E Department?	78%
Q42	When you were first admitted, did you mind sharing a sleeping area, for example a room or bay, with patients of the opposite sex?	78%
Q44	Did you mind being moved from one room or ward to another?	78%
Q76	Do you have any special dietary requirements (e.g. vegetarian, diabetic, food allergies)?	78%
Q78	Were you ever unable to eat during mealtimes (e.g. because you were away from the ward, recovery from surgery etc)?	78%
Q95	In your opinion, were there enough nurses on duty to care for you in hospital?	78%
Q101	How much information about your condition or treatment was given to you?	78%
Q114	Did you ever request pain relief medication?	78%
Q14	While you were in the A&E Department, did you have confidence and trust in the doctors and nurses examining and treating you?	77%
Q27	Was your admission date changed by the hospital?	77%
Q65	How would you rate the courtesy of the hospital porters?	77%
Q69	Were you ever bothered by other patients' visitors?	77%
Q90	In your opinion, did the doctors who treated you know enough about your condition or treatment?	76%
Q105	Did you find someone on the hospital staff to talk to about your worries and fears?	76%
Q120	During your stay in hospital, did you have any tests, x-rays or scans other than blood or urine tests?	76%
Q165	After leaving hospital, do you think you received enough care and assistance from health or social services?	76%
Q66	Were the visiting times convenient for your friends and family?	75%

4.2 Additional areas for inclusion

One question on the questionnaire survey asked participants, *"Are there any additional areas you feel should be included in a national survey on patient experience?"* A total of 49 participants answered the question, and, of those 42% (n = 21), indicated that there were additional areas. Thirty-three questions / question areas were identified around the following broad areas were identified:

- Family and carers
- Health service characteristics
- Patient characteristics
- Patient journey
- Patient outcome
- Service
- Supports

These are presented in Table 4 in more detail, with, where provided by the participant, a rationale for inclusion. Questions about whether these should be included in the NPE questionnaire were asked in the Round 2 survey and while it may not be possible to incorporate these into the current development, consideration may to be given to these areas at a later time.

Table 4: Additional areas identified by Delphi participants for inclusion in the NPE questionnaire

Question	Rationale
Family and carers	
Possibility of including questions on family or carers experience of the hospital particularly where the patient is unable to speak for themselves.	None provided
If you had family, carer or friend with you during your admission did they feel included in decisions with you.	None provided
...did you have the opportunity to have a family member, carer or friend with you if you wished?	None provided
Health service/system characteristics	
Would be interesting to know if any patients had difficulty complying with expected behaviours e.g. non-smoking campus	None provided
On discharge- maybe more specific questions about 1) what ward they were on 2) next steps	None provided
Dealing with administration in relation to admissions, billing procedures and other queries	None provided
Opinion on charges applied to patients in public wards who have private insurance e.g. being charged almost €900 for a bed in a 6 bedded mixed- gender ward with one toilet.	None provided
Patient characteristics	

Question	Rationale
Patients' self assessed health behaviours	It will be important to be able to have this information on patients (either via the questionnaire or matching with administrative data) for good analysis to be undertaken
'Did you feel you had a negative experience on the basis of your...?' and ask specifically and explicitly about religious identity, gender identity, socioeconomic class, education level, nationality, refugee status, etc. availability of internet and television services	In addition, I know in the final section there was a question about whether the patient had any negative experiences...I think this really should explicitly ask the question outlined. In this way, we can identify whether there are any sub-groups of patients who are, or who feel that they are, receiving poor treatment.
Patient journey	
Route to and duration before entry	None provided
Include a question on length of stay or frequency of admissions.	Frequent or long admissions can take the mystery out of the workings of wards and hospitals. Filling in a survey after one admission might give very different answers to someone filling in the survey after weeks in hospital.
Section on pre-hospital care if accessed; from call taker experience and ambulance service personnel.	None provided
Not clear in the survey if patients who are not admitted but attend for ambulatory care e.g. out-patients?	None provided
Ask the participant about suitability of appointment times.	Person centred care would provide flexibility for those working or with other commitments.
Patient outcome	
How would you rate your preparation for discharge i.e. did you feel ready to go home?	We need feedback on this issue.
How did you cope when you went home?	We need feedback on this issue.
Are they aware of going to GP or OPD after discharge? Do they now (go to the GP or OPD) and understand why?	None provided
Do they understand changes made to medications as a result of admission?	None provided
With information provided are you able to better manage your own condition?	None provided
'Did the time you had to wait to access care negatively impact your health?' or something in this vein	Wait times for accessing care are a huge issue. I know there was one question on wait times, but perhaps another question on the impact of wait times on the patient.
Service received	

Question	Rationale
Did you experience difficulty contacting the hospital when you were at home.	Difficulty getting through or getting the correct department or person can cause frustration, inadequate preparation for procedures, appointments missed.
Was information provided in a format and language that you could easily understand?	None provided
Ensuring ward notes are maintained for each patient - for in relation to person centre care	For instance a severe allergic reaction to an anaesthetic (nausea, vomiting) was not logged in this patient's experience - this oversight was only discovered years later on asking what this particular anaesthetic was, to avoid a repeat experience during a similar, subsequent surgery.
Were patients informed in a timely manner if things went wrong.	Open Disclosure has been rolled out in all hospitals and maybe a question on patients knowledge of this would be appropriate.
Did the health care professional confirm that you understood the information provided.	This type of question may provide data on staff awareness of communication and patients understanding.
Did they **see** Health Professionals washing their hands?	None provided
Supports	
If the expertise in the area of your condition lies outside this jurisdiction, do you feel that there was sufficient liaison to ensure appropriate and effective treatment and management of your condition?	Rare Diseases/Presentations are poorly represented in general in data collection opportunities which may improve service provision....these conditions are individually rare but collectively quite common
Access to additional support such as interpreter services or literacy support, physical disability aids not mentioned.	None provided
What could have made a difference to how you/your family coped when you went home?	We need feedback on this issue.

4.3 Additional comments

Participants were asked if they wished to make any additional comments at the end of the first round; their additional comments focused on four main areas. First, the participants were complimentary about the survey questions noting that it would be: " *A very good, thorough survey", "Great questions overall for a national patient survey", "All of the questions seem like sensible questions"* and *"It is hard to eliminate any of these questions".* Participants indicated they were also particularly happy to have been asked to take part in the Delphi study, with two individuals commenting on this as follows:

"Thank you for asking us as staff to take part in this review of patient experience in our hospitals. It is great to be asked."
"Thank you for including me in this important survey. Best of luck in its further development."

Some participants highlighted overlap between questions with comments such as: *"A lot of overlap in the questions included", "Certain sections contained a lot of overlap",* and *"Some of the questions are linked to others so difficult to answer"*. One person recommended:

"Rephrasing to reduce duplication and ensure survey is concise and is easy to use whilst still gaining valuable insight into practices and areas for improvement."

The importance of having a short easy to answer survey was raised by a small number of participants and it was suggested that:
"This is a potentially very long survey with many required questions. I would be concerned at the effect of this on completion of the questionnaire."
"I think the shorter the survey the more likely patients will be happy to complete it. It would be useful to keep survey as short as possible."

A small number of other comments were made. One related to the use of a different response category (using 'High priority', 'Medium priority', and 'Low priority') rather than "include" or "exclude". Another referred to the wording of the questions on the questionnaire noting that:

"Some of the questions are presented / worded with a negative bias, this can influence patients responses".

4.4 Summary: Round 1

In summary, using a cut-off point of 75% of participants indicating that a question should "probably" or "definitely" be included resulted in a high level of agreement about the key questions for inclusion in the NPE questionnaire. Despite this, a considerable number of additional areas were identified for consideration in Round 2. Commentary was provided in respect of four key areas. First, individuals were very complimentary about the questions and the survey overall;. second, participants welcomed an opportunity to take part. Concern was expressed about the potential length of the survey and finally, it was noted that there could be potential for re-phrasing questions to reduce the numbers included.

5.0 Integration of findings from the 1st Round of the Delphi study with focus group findings

As noted earlier, the Delphi methodology facilitates the co-construction of knowledge by enabling a process of individual feedback while taking account of group opinion. In the overall National Patient Experience Programme (NPEP) development, focus groups with data users (n = 2) and patients (n = 6) were undertaken by personnel from the NPEP prior to the commencement of the Delphi study. The integration of this data into the Delphi study was discussed with the Delivery and Advisory Groups and a decision to present the findings to Delphi panel participants in the second round of the study was made. Consequently, in addition to providing the usual information emerging from the first round of the Delphi Study, information on the views emerging from the focus groups were also provided for participants in the second round.

This section presents the findings in respect of the integration of data from these three sources which were drawn from:

1. Delphi panel which included 58 participants;
2. Patient focus groups, which included six focus groups with a total of 48 participants; and
3. Data users' focus groups, which included two focus groups with a total of 14 participants.

In integrating the data, a consensus level was set on the basis of a clear majority cut-off for each data source as follows:

- **Delphi panel**. The cut-off point used was 75%. All questions where 75% or more of the participants agreed should "probably" or "definitely" be included were identified. In total, 105 questions were identified by adopting this level of consensus.
- **Patient focus groups.** A consensus level of 67% was identified (that is, where 4 of the 6 groups agreed the question should be "included" or "included but combined with another question"). This cut off point was used since it reflected the views arising from the majority of the focus groups. In total, 133 questions were identified using this approach.
- **Data users' focus groups.** A consensus level of 100% was identified (that is both focus groups had to indicate a question should be "included" or "included but combined or merged with another question). A consensus level of 100% was adopted as only two groups were conducted and a majority view was required. In total, 96 questions were identified using this criteria.

5.1 Key findings from integration of the data

Figure 6 illustrates the integration of the three sources of data in respect of 189 questions and, as can be seen, this resulted in considerable consensus across each of the three groups.

- 64 questions where all three groups (Delphi panel, patient focus groups and data users' focus groups) agreed they should be included in the NPE questionnaire were identified.
- A further 41 questions were not selected by any group for inclusion.
- Six questions were chosen by the Delphi panel that had not been prioritised by either of the other two groups.
- Four questions were chosen by the data users' group that had not been prioritised by either of the other two groups.
- 16 questions were chosen by the patient focus groups that had not been prioritised by either of the other two groups.
- In addition to the 64 questions where all groups agreed, 30 questions were agreed between the patient focus group and the Delphi panel.
- 23 questions were agreed by the data users' focus group and patient focus group.

Figure 6: Venn diagram identifying the level of consensus across three different data sources
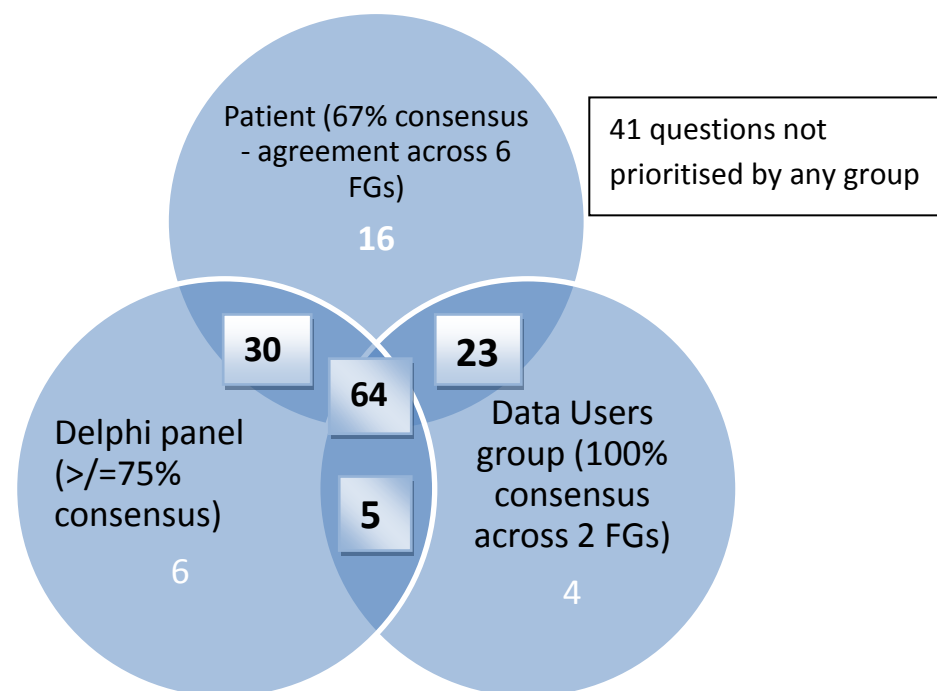
As highlighted in Figure 6, there was agreement across each of the three groups, Delphi panel, patient focus groups and data users' focus groups on 64 questions. These 64 questions are now presented Table 5.

Table 5: Questions where there is broad consensus between Delphi panel, data user and patient focus groups (n = 64)

Question Number	Question
Accident & Emergency	
Q12	Were you given enough privacy when being examined or treated in the A&E Department?
Q16	While you were in the A&E Department, did a doctor or nurse explain your condition and treatment in a way you could understand?
Q19	In your opinion, how clean was the A&E Department?
Q21	Overall, did you feel you were treated with respect and dignity while you were in the A&E Department?
Waiting Lists or Planned Admissions	
Q27	Was your admission date changed by the hospital?
All Types of Admissions	
Q39	How would you rate the courtesy of the staff who admitted you?
Hospital & Ward	
Q47	When you needed to use a toilet or bathroom, was there a suitable one located close by?
Q48	When you needed help from staff getting to the bathroom or toilet, did you get it in time?
Q51	Were you given enough privacy while you were on the ward?
Q56	In your opinion, how clean was the hospital room or ward that you were in?
Q57	How clean were the toilets and bathrooms that you used in hospital?
Q60	Did you have somewhere to keep your personal belongings whilst on the ward?
Q61	Did staff wear name badges?
Q62	Did the staff treating and examining you introduce themselves?
Q65	How would you rate the courtesy of the hospital porters?
Hospital & Ward - Visitors	
Q69	Were you ever bothered by other patients' visitors?
Hospital & Ward - Food	
Q70	How would you rate the hospital food?
Q74	Were you offered a choice of food?
Q76	Do you have any special dietary requirements (e.g. vegetarian, diabetic, food allergies)?
Q77	Was the hospital food suitable for your dietary needs?
Q78	Were you ever unable to eat during mealtimes (e.g. because you were away from the ward, recovery from surgery etc)?
Q79	Were you offered a replacement meal at another time?
Q80	Did you get enough help from staff to eat your meals?
Q81	How would you rate the courtesy of the catering staff?
Doctors	
Q84	If you had any worries or fears about your condition or treatment, did a doctor discuss them with you?
Q86	Did you have confidence and trust in the doctors treating you?
Q89	How would you rate the courtesy of your doctors?
Nurses	
Q92	If you had any worries or fears about your condition or treatment, did a nurse discuss them with you?
Q93	Did you have confidence and trust in the nurses treating you?
Q97	How would you rate the courtesy of your nurses?

		Your Care & Treatment
	Q100	Were you involved as much as you wanted to be in decisions about your care and treatment?
	Q101	How much information about your condition or treatment was given to you?
	Q104	If your family or someone else close to you wanted to talk to a doctor, did they have enough opportunity to do so?
	Q109	Were you given enough privacy when discussing your condition or treatment?
	Q110	Were you given enough privacy when being examined or treated?
		Pain
	Q117	Do you think the hospital staff did everything they could to help control your pain?
		Tests
	Q120	During your stay in hospital, did you have any tests, x-rays or scans other than blood or urine tests?
	Q121	Were you told in advance when your tests, x-rays or scans were going to take place?
	Q123	Did a member of staff explain why the scheduled tests were not performed on time?
		Treatments
	Q125	Before you received any treatments (e.g. an injection, dressing, physiotherapy) did a member of staff explain what would happen?
	Q127	Did you feel you could refuse any treatment that you did not agree with or did not want?
		Operations & Procedures
	Q131	During your stay in hospital, did you have an operation or procedure?
	Q132	Beforehand, did a member of staff explain the risks and benefits of the operation or procedure in a way you could understand?
	Q134	Beforehand, did a member of staff answer your questions about the operation or procedure in a way you could understand?
	Q135	Beforehand, were you told how you could expect to feel after you had the operation or procedure?
	Q139	After the operation or procedure, did a member of staff explain how the operation or procedure had gone in a way you could understand?
		Leaving Hospital
	Q140	Did you feel you were involved in decisions about your discharge from hospital?
	Q143	On the day you left hospital, was your discharge delayed for any reason?
	Q149	Before you left hospital, did the doctors and nurses spend enough time explaining about your health and care after you arrive home?
	Q150	Before you left hospital, were you given any written or printed information about what you should or should not do after leaving hospital?
	Q151	Did a member of staff explain the purpose of the medicines you were to take at home in a way you could understand?
	Q152	Did a member of staff tell you about medication side effects to watch for when you went home?
	Q154	Were you given clear written or printed information about your medicines?
	Q156	Did hospital staff take your family or home situation into account when planning your discharge?
	Q157	Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you?
	Q159	Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?
	Q161	Did hospital staff discuss with you whether you may need any further health or social care services after leaving hospital? (e.g. services from a GP, physiotherapist or community nurse, or assistance from social services or the voluntary sector).

	Overall Experience	
Q168	Overall, did you feel you were treated with respect and dignity while you were in the hospital?	
Q169	Overall, were you treated with kindness and understanding while you were in the hospital?	
Q170	Overall... (Please rate)	
Q172	Did you see, or were you given, any information explaining how to complain to the hospital about the care you received?	
	Other Comments	
Q196	Was there anything particularly good about your hospital care?	
Q197	Was there anything that could be improved?	
Q198	Any other comments?	

As noted in the methodology section, information on the levels of agreement across each of the three groups was provided for participants in Round 2 of the Delphi study.

6.0 Findings: Round 2

The findings from the second and final round of the study are presented here. These findings are presented in two main parts:

1. The top 100 questions prioritised by the panel and general commentary about the questions
2. Consideration of validity in respect of the:

    o the patient journey through the service
    o key concepts of patient experience
    o HIQA's *National Standards for Safer Better Healthcare.*

6.1 Questions prioritised

This section presents the findings from Round 2 of the Delphi panel deliberations. The Round 2 questionnaire included feedback from Round 1 of the survey and also findings from the focus group discussions that took place with patients (n=6 focus groups; 48 participants) and data users (n=2; 14 participants).

Table 6 presents the overall results of the Round 2 of the Delphi panel. In total, 100 questions are ranked according the mean and all questions with a mean value of 75 or higher were included. Those with the highest mean value are ranked highest since a high mean value represents a high group opinion about the inclusion of the question. Within this, 35 questions had a mean of 90 or higher. Those with the lowest mean value are ranked lowest and 18 questions had a mean value of less than 80. The standard deviation is also provided and this presents a representation of the spread of views. A low standard deviation represents a lower level of different views, while a high standard deviation represents a wider range of views. The standard deviation ranged from 7.76 to 30.64 and, as expected, those questions with a higher mean value, generally have a lower standard deviation.

Table 6: Round 2. Top 100 questions prioritised by the Delphi panel

Rank	Question number	Round 2 Questionnaire	Mean	Std. Deviation
1	Q110	Were you given enough privacy when being examined or treated?	95.67	7.76
2	Q196	Was there anything particularly good about your hospital care?	95.40	9.31
3	Q21	Overall, did you feel you were treated with respect and dignity while you were in the A&E Department?	95.29	8.78
4	Q109	Were you given enough privacy when discussing your condition or treatment?	95.18	9.61
5	Q139	After the operation or procedure, did a member of staff explain how the operation or procedure had gone in a way you could understand?	94.58	8.65
6	Q169	Overall, were you treated with kindness and understanding while you were in the hospital?	94.56	10.04
7	Q168	Overall, did you feel you were treated with respect and dignity while you were in the hospital?	94.32	10.14
8	Q62	Did the staff treating and examining you introduce themselves?	94.28	9.71
9	Q103	Was your diagnosis explained to you in a way that you could understand?	94.08	10.86
10	Q140	Did you feel you were involved in decisions about your discharge from hospital?	93.95	9.38
11	Q197	Was there anything that could be improved?	93.73	11.19
12	Q12	Were you given enough privacy when being examined or treated in the A&E Department?	93.33	10.20
13	Q124	Did a doctor or nurse explain the results of the tests in a way that you could understand?	93.26	11.11
14	Q159	Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	93.24	15.85
15	Q149	Before you left hospital, did the doctors and nurses spend enough time explaining about your health and care after you arrive home?	93.18	11.43
16	Q80	Did you get enough help from staff to eat your meals?	93.17	9.93
17	Q100	Were you involved as much as you wanted to be in decisions about your care and treatment?	93.03	11.14
18	Q151	Did a member of staff explain the purpose of the medicines you were to take at home in a way you could understand?	93.00	12.87
19	Q117	Do you think the hospital staff did everything they could to help control your pain?	92.72	12.12
20	Q83	When you had important questions to ask a doctor, did you get answers that you could understand?	92.71	10.55
21	Q132	Beforehand, did a member of staff explain the risks and benefits of the operation or procedure in a way you could understand?	92.61	13.81
22	Q134	Beforehand, did a member of staff answer your questions about the operation or procedure in a way you could understand?	92.11	17.30
23	Q85	Did you feel you had enough time to discuss your care and treatment with a doctor?	91.79	11.77
24	Q198	Any other comments?	91.57	16.91
25	Q135	Beforehand, were you told how you could expect to feel after you had the operation or procedure?	91.13	17.93

Rank	Question number	Round 2 Questionnaire	Mean	Std. Deviation
26	Q157	Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you?	91.10	14.43
27	Q70	How would you rate the hospital food?	90.84	13.35
28	Q13	When you had important questions to ask doctors and nurses in the A&E Department, did you get answers that you could understand?	90.78	13.18
29	Q56	In your opinion, how clean was the hospital room or ward that you were in?	90.76	13.67
30	Q92	If you had any worries or fears about your condition or treatment, did a nurse discuss them with you?	90.44	17.89
31	Q51	Were you given enough privacy while you were on the ward?	90.42	14.02
32	Q48	When you needed help from staff getting to the bathroom or toilet, did you get it in time?	90.37	21.20
33	Q152	Did a member of staff tell you about medication side effects to watch for when you went home?	90.21	15.13
34	Q61	Did staff wear name badges?	90.19	14.11
35	Q156	Did hospital staff take your family or home situation into account when planning your discharge?	90.03	15.06
36	Q127	Did you feel you could refuse any treatment that you did not agree with or did not want?	89.69	18.19
37	Q91	When you had important questions to ask a nurse, did you get answers that you could understand?	89.23	15.84
38	Q16	While you were in the A&E Department, did a doctor or nurse explain your condition and treatment in a way you could understand?	89.20	20.92
39	Q97	How would you rate the courtesy of your nurses?	89.17	18.87
40	Q77	Was the hospital food suitable for your dietary needs?	88.93	18.32
41	Q96	If you ever needed to talk to a nurse, did you get the opportunity to do so?	88.91	14.54
42	Q131	During your stay in hospital, did you have an operation or procedure?	88.73	20.14
43	Q57	How clean were the toilets and bathrooms that you used in hospital?	88.59	15.84
44	Q150	Before you left hospital, were you given any written or printed information about what you should or should not do after leaving hospital?	88.38	22.50
45	Q89	How would you rate the courtesy of your doctors?	88.17	19.73
46	Q84	If you had any worries or fears about your condition or treatment, did a doctor discuss them with you?	88.00	22.91
47	Q104	If your family or someone else close to you wanted to talk to a doctor, did they have enough opportunity to do so?	87.97	19.43
48	Q39	How would you rate the courtesy of the staff who admitted you?	87.96	19.18
49	Q155	Did a member of staff tell you about any danger signals you should watch for after you went home?	87.80	23.61
50	Q101	How much information about your condition or treatment was given to you?	87.70	17.53
51	Q79	Were you offered a replacement meal at another time?	87.66	15.86
52	Q153	Were you told how to take your medication in a way you could understand?	87.53	24.15

| Rank	Question number	Round 2 Questionnaire	Mean	Std. Deviation
53	Q47	When you needed to use a toilet or bathroom, was there a suitable one located close by?	87.31	20.53
54	Q141	Were you given enough notice about when you were going to be discharged?	87.10	17.66
55	Q78	Were you ever unable to eat during mealtimes (e.g. because you were away from the ward, recovery from surgery etc)?	87.09	17.06
56	Q178	What was your year of birth?	87.00	22.42
57	Q125	Before you received any treatments (e.g. an injection, dressing, physiotherapy) did a member of staff explain what would happen?	86.95	25.19
58	Q162	Do you feel that you received enough information from the hospital on how to manage your condition after your discharge?	86.95	23.48
59	Q126	Before you received any treatments (e.g. an injection, dressing, physiotherapy) did a member of staff explain any risks and/or benefits in a way you could understand?	86.69	21.58
60=	Q142	Were your family or someone close to you given enough notice about your discharge?	86.55	17.57
60=	Q177	Are you male or female?	86.55	19.20
61	Q74	Were you offered a choice of food?	86.37	18.45
62	Q19	In your opinion, how clean was the A&E Department?	86.29	17.63
63	Q105	Did you find someone on the hospital staff to talk to about your worries and fears?	86.13	20.67
64	Q1	Was your most recent hospital stay planned in advance or an emergency?	85.95	17.53
65	Q161	Did hospital staff discuss with you whether you may need any further health or social care services after leaving hospital? (e.g. services from a GP, physiotherapist or community nurse, or assistance from social services or the voluntary sector).	85.85	23.80
66	Q102	While you were in hospital, were you told your diagnosis (explanation of what was wrong with you)?	85.59	27.51
67	Q143	On the day you left hospital, was your discharge delayed for any reason?	85.55	20.01
68=	Q86	Did you have confidence and trust in the doctors treating you?	85.51	27.08
68=	Q93	Did you have confidence and trust in the nurses treating you?	85.51	26.62
69	Q170	Overall... (Please rate)	85.23	25.70
70	Q154	Were you given clear written or printed information about your medicines?	85.00	25.89
71	Q60	Did you have somewhere to keep your personal belongings whilst on the ward?	84.96	23.40
72	Q158	Did hospital staff tell you when you could resume your usual activities, such as when to go back to work or drive a car?	84.31	21.58
73	Q72	Was there healthy food on the hospital menu?	84.26	25.43
74	Q136	Did you have enough time to discuss your operation or procedure with the consultant?	84.19	23.91
75	New question	Question on whether the patient was informed in a timely manner if things went wrong (in line with open disclosure)	83.73	22.50

Rank	Question number	Round 2 Questionnaire	Mean	Std. Deviation
76	Q160	Did hospital staff discuss with you whether you would need any additional equipment in your home, or any adaptations made to your home, after leaving hospital?	83.44	24.25
77	Q121	Were you told in advance when your tests, x-rays or scans were going to take place? [Prioritised by all groups]	82.62	25.96
78	Q173	Did you want to complain about the care you received in hospital?	82.50	22.18
79	Q82	Was there one doctor in overall charge of your care?	81.81	26.40
80	Q22	Following arrival at the hospital, how long did you wait before being admitted to a bed on a ward?	81.73	25.59
81	Q76	Do you have any special dietary requirements (e.g. vegetarian, diabetic, food allergies)?	81.49	25.38
82	Q11	While you were in the A&E Department, how much information about your condition or treatment was given to you?	81.48	24.37
83	Q138	Before the operation or procedure, did the anaesthetist or another member of staff explain how he or she would put you to sleep or control your pain in a way you could understand?	81.16	27.01
84	Q133	Beforehand, did a member of staff explain what would be done during the operation or procedure?	81.08	30.20
85	Q172	Did you see, or were you given, any information explaining how to complain to the hospital about the care you received?	81.05	28.48
86	Q81	How would you rate the courtesy of the catering staff?	80.40	24.97
87	Q144	What was the MAIN reason for the delay? (Tick ONE box only)	80.38	24.36
88	Q14	While you were in the A&E Department, did you have confidence and trust in the doctors and nurses examining and treating you?	80.11	25.93
89	Q59	Did you feel threatened during your stay in hospital by other patients or visitors?	80.05	22.16
90	Q95	In your opinion, were there enough nurses on duty to care for you in hospital?	79.86	26.88
91	Q123	Did a member of staff explain why the scheduled tests were not performed on time?	79.33	27.69
92	Q122	Were your scheduled tests, x-rays or scans performed on time? [Prioritised by both DP and Pt groups]	79.15	25.20
93	Q75	Did you get the food you ordered?	78.43	26.30
94	Q6	Overall, did the ambulance crew treat you with respect and dignity?	78.17	30.53
95	Q98	In your opinion, did the nurses who treated you know enough about your condition or treatment?	78.02	30.10
96	Q9	Overall, how would you rate the care you received from the ambulance service?	77.91	30.64
97	Q106	Do you feel you got enough emotional support from hospital staff during your stay?<	77.78	25.42
98	Q120	During your stay in hospital, did you have any tests, x-rays or scans other than blood or urine tests?	77.77	30.60

Note. Tied ranks on two items give 98 rank positions; 100 items are in the table

6.2 Stability between rounds

As noted in the previous section, the integration of data from Round 1 of the Delphi study with the focus group findings showed a consensus around the top 64 questions. This consensus was reiterated in Round 2 findings where 62 of these 64 questions were prioritised for inclusion in the top 100 questions for the NPE questionnaire. A further 37 questions included in the top 100 were identified by two groups and only one question by one group only (Figure 7). These findings suggest a high level of stability between Delphi Round 1 and Round 2.

Figure 7: Overlap between questions prioritised in Round 1 and Round 2
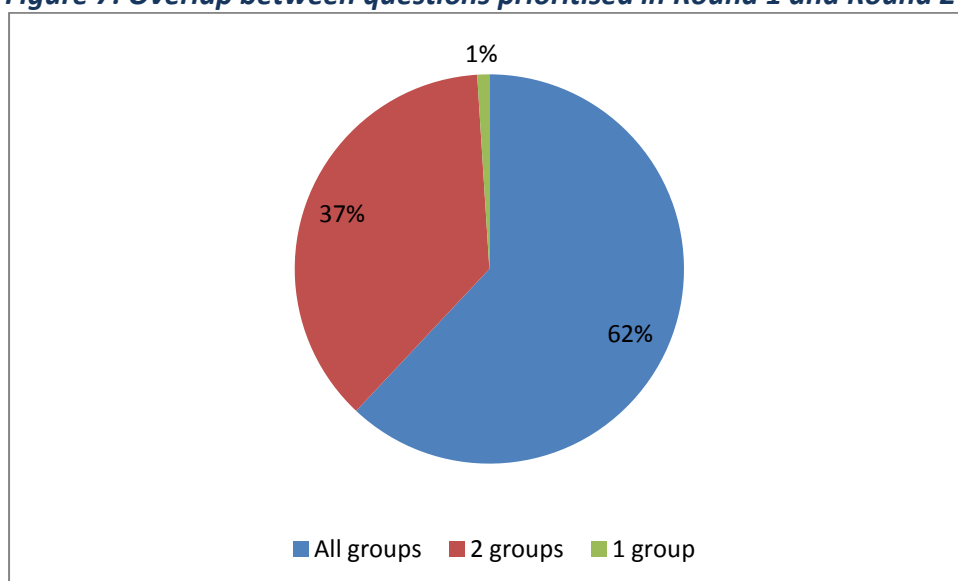
In addition to providing information about individual questions, participants on the Delphi panel were asked whether they wished to make any comments. These are presented in the next section.

6.3 Other comments

In response to the question, *"Do you wish to make any comments?",* 15 participants responded. Similar to the Round 1 commentary, participants welcomed their involvement in the study noting they were, "*delighted to know about the survey and take part in it*". However, one participant noted that:

> "*I find it difficult to understand how all the time and money invested in this project will help the most important person "the patient".*"

Other comments related to the themes and questions. One person noted that:

> "*Too many questions may put people off. The sections are good but could still be too much if all these are included.*"

A small number of comments related to the questions and their wording with participants suggesting that: "*Questions here seem unclear about the intention of the question*", "*Many of the questions can be merged",* and *"Still some duplication, but improving*".

Specific questions were also highlighted with one participant indicating that Questions 101 and 110 were both "*subjective questions"* and queried how "*a patient (would) know whether a Dr or Nurse knew enough about a condition?"* It was also noted that it would be better to use standard questions available such as those related to demography available through the Healthy Ireland survey.

Three specific recommendations were made as follows:

- *"The inclusion of questions examining the experience of family members and carers. This is critical to the patient journey and experience, and is particularly important in instances where the patient has limited capacity and relies heavily on their carer."*
- *"A parallel set of questions needs to be developed for community setting - proactive healthcare outside the acute hospital setting is also very important and becoming more so."*
- *"There is no question on number of previous times admitted to hospital which makes a big difference to the patient's experience".*

7.0 Findings: Considerations relating to the prioritised set of questions

The two-round Delphi study resulted in the prioritisation of 60 key questions for inclusion in a patient experience questionnaire with a further 40 ranked for inclusion if required. Some issues arising in respect of the prioritised questions are presented here for consideration so that they can be taken in to account in further deliberations taking place with Picker Institute Europe.

The Beryl Institute (2016) definition of patient experience was used to guide this study and this definition is as follows:

> "*The sum of all interactions, shaped by an organisation's culture, that influence patient perceptions, across the continuum of care*" (The Beryl Institute, 2016).

The definition is particularly helpful because it facilitates a comprehensive understanding of patient experience that takes account of all interactions; the continuum of care; and organisational culture. With the exception of one question (ranked 65 in Table 6) focused on open disclosure which emerged from the "additional areas" identified in Round 1 of the Delphi study, all other prioritised questions have previously been tested and validated by Picker Institute Europe. Each individual question is therefore valid and relevant to the measurement of patient experience. The complexity of this concept, however, means that some consideration needs to be given to the extent to which the prioritised set of questions as a whole meet the criteria for conceptual comprehensiveness and cultural relevance to the Irish situation. Consideration is also given in this section to the views emerging from focus groups in respect of the combination or merging of questions with each other.

Findings in respect of each of these areas are now considered.

7.1 Themes and sub-themes relating to the patient journey
This section considers whether all themes and sub-themes related to the patient journey can be captured using the top 60 and top 100 questions as prioritised by the Delphi panel in Round 2 (Table 7).

Table 7: Prioritised questions according to the patient journey (Top 100)

Rank	Question number	Question
		Ambulance
64	Q1	Was your most recent hospital stay planned in advance or an emergency?
94	Q6	Overall, did the ambulance crew treat you with respect and dignity?
96	Q9	Overall, how would you rate the care you received from the ambulance service?
		A&E
82	Q11	While you were in the A&E Department, how much information about your condition or treatment was given to you?
12	Q12	Were you given enough privacy when being examined or treated in the A&E Department?
28	Q13	When you had important questions to ask doctors and nurses in the A&E Department, did you get answers that you could understand?
88	Q14	While you were in the A&E Department, did you have confidence and trust in the doctors and nurses examining and treating you?
38	Q16	While you were in the A&E Department, did a doctor or nurse explain your condition and treatment in a way you could understand?
62	Q19	In your opinion, how clean was the A&E Department?
3	Q21	Overall, did you feel you were treated with respect and dignity while you were in the A&E Department?
80	Q22	Following arrival at the hospital, how long did you wait before being admitted to a bed on a ward?
		Waiting Lists or Planned Admissions
		NONE PRIORITISED IN TOP 100
		All Types of Admissions
48	Q39	How would you rate the courtesy of the staff who admitted you?
		Hospital & Ward
53	Q47	When you needed to use a toilet or bathroom, was there a suitable one located close by?
32	Q48	When you needed help from staff getting to the bathroom or toilet, did you get it in time?
31	Q51	Were you given enough privacy while you were on the ward?
29	Q56	In your opinion, how clean was the hospital room or ward that you were in?
43	Q57	How clean were the toilets and bathrooms that you used in hospital?
89	Q59	Did you feel threatened during your stay in hospital by other patients or visitors?
71	Q60	Did you have somewhere to keep your personal belongings whilst on the ward?
34	Q61	Did staff wear name badges?
8	Q62	Did the staff treating and examining you introduce themselves?
		Hospital & Ward - Visitors
		NONE PRIORITISED IN THE TOP 100
		Hospital & Ward - Food
27	Q70	How would you rate the hospital food?
75	Q72	Was there healthy food on the hospital menu?
61	Q74	Were you offered a choice of food?

Rank	Question number	Question
93	Q75	Did you get the food you ordered?
81	Q76	Do you have any special dietary requirements (e.g. vegetarian, diabetic, food allergies)?
40	Q77	Was the hospital food suitable for your dietary needs?
55	Q78	Were you ever unable to eat during mealtimes (e.g. because you were away from the ward, recovery from surgery etc)?
51	Q79	Were you offered a replacement meal at another time?
16	Q80	Did you get enough help from staff to eat your meals?
86	Q81	How would you rate the courtesy of the catering staff?
		Doctors
79	Q82	Was there one doctor in overall charge of your care?
20	Q83	When you had important questions to ask a doctor, did you get answers that you could understand?
46	Q84	If you had any worries or fears about your condition or treatment, did a doctor discuss them with you?
23	Q85	Did you feel you had enough time to discuss your care and treatment with a doctor?
68=	Q86	Did you have confidence and trust in the doctors treating you?
45	Q89	How would you rate the courtesy of your doctors?
		Nurses
37	Q91	When you had important questions to ask a nurse, did you get answers that you could understand?
30	Q92	If you had any worries or fears about your condition or treatment, did a nurse discuss them with you?
68=	Q93	Did you have confidence and trust in the nurses treating you?
90	Q95	In your opinion, were there enough nurses on duty to care for you in hospital?
41	Q96	If you ever needed to talk to a nurse, did you get the opportunity to do so?
39	Q97	How would you rate the courtesy of your nurses?
95	Q98	In your opinion, did the nurses who treated you know enough about your condition or treatment?
		Your Care & Treatment
17	Q100	Were you involved as much as you wanted to be in decisions about your care and treatment?
50	Q101	How much information about your condition or treatment was given to you?
66	Q102	While you were in hospital, were you told your diagnosis (explanation of what was wrong with you)?
9	Q103	Was your diagnosis explained to you in a way that you could understand?
47	Q104	If your family or someone else close to you wanted to talk to a doctor, did they have enough opportunity to do so?
63	Q105	Did you find someone on the hospital staff to talk to about your worries and fears?
97	Q106	Do you feel you got enough emotional support from hospital staff during your stay?
4	Q109	Were you given enough privacy when discussing your condition or treatment?
1	Q110	Were you given enough privacy when being examined or treated?
		Pain

Rank	Question number	Question
19	Q117	Do you think the hospital staff did everything they could to help control your pain?
		Tests
98	Q120	During your stay in hospital, did you have any tests, x-rays or scans other than blood or urine tests?
77	Q121	Were you told in advance when your tests, x-rays or scans were going to take place?
92	Q122	Were your scheduled tests, x-rays or scans performed on time?
91	Q123	Did a member of staff explain why the scheduled tests were not performed on time?
13	Q124	Did a doctor or nurse explain the results of the tests in a way that you could understand?
		Treatments
57	Q125	Before you received any treatments (e.g. an injection, dressing, physiotherapy) did a member of staff explain what would happen?
59	Q126	Before you received any treatments (e.g. an injection, dressing, physiotherapy) did a member of staff explain any risks and/or benefits in a way you could understand?
36	Q127	Did you feel you could refuse any treatment that you did not agree with or did not want?
		Operations & Procedures
42	Q131	During your stay in hospital, did you have an operation or procedure?
21	Q132	Beforehand, did a member of staff explain the risks and benefits of the operation or procedure in a way you could understand?
84	Q133	Beforehand, did a member of staff explain what would be done during the operation or procedure?
22	Q134	Beforehand, did a member of staff answer your questions about the operation or procedure in a way you could understand?
25	Q135	Beforehand, were you told how you could expect to feel after you had the operation or procedure?
74	Q136	Did you have enough time to discuss your operation or procedure with the consultant?
83	Q138	Before the operation or procedure, did the anaesthetist or another member of staff explain how he or she would put you to sleep or control your pain in a way you could understand?
5	Q139	After the operation or procedure, did a member of staff explain how the operation or procedure had gone in a way you could understand?
		Leaving Hospital
10	Q140	Did you feel you were involved in decisions about your discharge from hospital?
54	Q141	Were you given enough notice about when you were going to be discharged?
60=	Q142	Were your family or someone close to you given enough notice about your discharge?
67	Q143	On the day you left hospital, was your discharge delayed for any reason?
87	Q144	What was the MAIN reason for the delay? (Tick ONE box only)
15	Q149	Before you left hospital, did the doctors and nurses spend enough time

Rank	Question number	Question
		explaining about your health and care after you arrive home?
44	Q150	Before you left hospital, were you given any written or printed information about what you should or should not do after leaving hospital?
18	Q151	Did a member of staff explain the purpose of the medicines you were to take at home in a way you could understand?
33	Q152	Did a member of staff tell you about medication side effects to watch for when you went home?
52	Q153	Were you told how to take your medication in a way you could understand?
70	Q154	Were you given clear written or printed information about your medicines?
49	Q155	Did a member of staff tell you about any danger signals you should watch for after you went home?
35	Q156	Did hospital staff take your family or home situation into account when planning your discharge?
26	Q157	Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you?
72	Q158	Did hospital staff tell you when you could resume your usual activities, such as when to go back to work or drive a car?
14	Q159	Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?
76	Q160	Did hospital staff discuss with you whether you would need any additional equipment in your home, or any adaptations made to your home, after leaving hospital?
65	Q161	Did hospital staff discuss with you whether you may need any further health or social care services after leaving hospital? (e.g. services from a GP, physiotherapist or community nurse, or assistance from social services or the voluntary sector).
58	Q162	Do you feel that you received enough information from the hospital on how to manage your condition after your discharge?
		Overall Experience
7	Q168	Overall, did you feel you were treated with respect and dignity while you were in the hospital?
6	Q169	Overall, were you treated with kindness and understanding while you were in the hospital?
69	Q170	Overall... (Please rate)
85	Q172	Did you see, or were you given, any information explaining how to complain to the hospital about the care you received?
78	Q173	Did you want to complain about the care you received in hospital?
		Demographics
60=	Q177	Are you male or female?
56	Q178	What was your year of birth?
		Other Comments
2	Q196	Was there anything particularly good about your hospital care?
11	Q197	Was there anything that could be improved?
24	Q198	Any other comments?
		Additional Questions from Round 1
75	Non-	Question on whether the patient was informed in a timely manner if things

Rank	Question number	Question
	HIQA	went wrong (in line with open disclosure)

Overview of findings by themes and sub-themes relating to the patient journey

The questions presented in Table 8 include those with the 100 highest rankings in respect of themes identified by Picker Institute Europe in their library of questions and these show substantial differences in the number of questions included by individual theme.

Table 8: Overview of findings by themes and sub-themes

Theme	Number in top 60 questions prioritised
Ambulance	0
Accident & Emergency	4
Waiting lists or Planned Admissions	0
All Types of Admissions	1
Hospital & Ward	7
Hospital & Ward - Visitors	0
Hospital & Ward - Food	5
Doctors	4
Nurses	4
Care and Treatment	6
Pain	1
Tests	1
Treatments	3
Operations and Procedures	5
Leaving hospital	13
Overall experience	2
Demographics	1
Other comments	3

The findings also show, however, that some sections do not have any questions. In the top 60 questions, there are no questions about:

- the ambulance service;
- waiting lists or planned admissions; or
- visitors.

In the top 100 questions, there are no questions about:

- waiting lists or planned admissions and
- visitors.

While three questions relating to the ambulance service are included in the top 100 questions, this is not the case for the areas of "Waiting lists or planned admissions" or "Visitors". If questions are to be included about these two areas, it will be necessary to

draw questions that are currently ranked up to 10 places below the top 100 ranked items. Considerations in respect of these are now presented for each of the three areas below.

Ambulance

As noted earlier, the Delphi panel did not prioritise any questions in the top 60 around the theme "Ambulance services". The following three questions have the potential to be included:

Rank	Question #	Question
64	Q1	Was your most recent hospital stay planned in advance or an emergency?
94	Q6	Overall, did the ambulance crew treat you with respect and dignity?
96	Q9	Overall, how would you rate the care you received from the ambulance service?

Based on the above, some consideration may need to be given to the inclusion of Q6 ("*Overall, did the ambulance crew treat you with respect and dignity*?") in the top 60 questions. This question is the one ranked highest by the Delphi panel in this section. In the event that this question is included, an additional lead-in question (Q65) will be required in respect of the ambulance service.

Planned admissions and waiting list

The first question about "Planned admissions and waiting list" is ranked at 102 by the Delphi panel.

Rank	Question #	Question
102	Q27	Was your admission date changed by the hospital?

Some consideration may need to be given to the inclusion of Q27 ("*Was your admission date changed by the hospital?")* in the top 60 so that a question relating to the theme "Waiting lists or planned admissions" is included in the NPE questionnaire.

Visitors

The final area relates to the theme "Visitors" and the Delphi panel did not select any question relating to this area for inclusion in the top 100. The highest ranked question (rank 101) relating to visitors is Q69 ("*Were you ever bothered by other patients' visitors?")*. Some consideration may need to be given to the inclusion of this question in the top 60 so that this thematic area can be included.

Other issues to be considered relate to those areas where questions may be removed from the top 60 in order to accommodate additional entries.

Leaving hospital

The section on "Leaving hospital" has 13 questions (22%) in the top 60 priorities. The lowest ranked questions in this area are presented in Table 9.

In the event that some questions need to be removed from the top 60 questions, some consideration could be given to selecting these questions from the thematic area "Leaving hospital".

Table 9: Considerations for removal of questions from top 60

Rank	Question number	Questions on leaving hospital
52	Q153	Were you told how to take your medication in a way you could understand?
54	Q141	Were you given enough notice about when you were going to be discharged?
58	Q162	Do you feel that you received enough information from the hospital on how to manage your condition after your discharge?

While Q142 ("*Were your family or someone close to you given enough notice about your discharge?*") is ranked at 60, this question is one of only two questions included that are relevant to the concept of "involvement of family and friends" discussed below and, consequently, consideration should be given to the continued inclusion of this question.

Summary thematic areas related to the patient journey

The findings relating to thematic areas relating to the patient journey show differences in the number of questions included in each theme and three themes do not have any questions in the top 60. These themes are "Ambulance service", "Waiting lists or planned admissions", and "Visitors". In respect of the theme "Ambulance service", there is no question in the top 60 but three in the top 100. Some areas have been highlighted for consideration, particularly in respect of Q96 ("*Overall, did the ambulance crew treat you with respect and dignity?*"). However, if included, this would also require a lead-in question.

In respect of the theme "Planned admissions and waiting list", some consideration may need to be given to Q27 ("*Was your admission date changed by the hospital?"),* currently ranked 102, to be included in the top 60. The highest ranked question (rank 101) by the Delphi panel relating to visitors is Q69 ("*Were you ever bothered by other patients' visitors?"*).

More than one in five (22%) questions ranked in the top 60 priorities relates to the theme "Leaving hospital". Three of the lower ranked questions (Q141, Q153, Q162) ranked between 52 and 58 have been identified as having the potential to be excluded from the top 60.

7.2 Concept of patient experience

Some consideration was given earlier on in this report to the term "patient experience" and it was noted that while there is an increasing focus on achieving a common definition this has not yet been accomplished. Picker Institute Europe has deliberated on this matter for many years and, in a recent joint publication with the University of Oxford (Fitzpatrick, et al., 2014), have identified the following areas in developing a "simple, conceptually grounded and unified model for assessing patient experience" (page 7):

1. **Respect for patient-centred values, preferences, and expressed needs,** including: cultural issues; the dignity, privacy and independence of patients and service users; an awareness of quality of life issues; and shared decision-making.
2. **Co-ordination and integration of care** across the health and social care system.
3. **Information, communication and education** on clinical status, progress, prognosis, and processes of care in order to facilitate autonomy, self-care and health promotion.
4. **Physical comfort** including pain management, help with activities of daily living, and clean and comfortable surroundings.
5. **Emotional support and alleviation of fear and anxiety** about such issues as clinical status, prognosis, and the impact of illness on patients, their families and their finances.
6. **Welcoming the involvement of family and friends**, on whom patients and service users rely, in decision-making and demonstrating awareness and accommodation of their needs as caregivers.
7. **Transition and continuity** as regards information that will help patients care for themselves away from a clinical setting, and co-ordination, planning, and support to ease transitions.
8. **Access to care with attention** for example, to time spent waiting for admission or time between admission and placement in a room in an in-patient setting, and waiting time for an appointment or visit in the out-patient, primary care or social care setting.

Consideration is now given to these areas in respect of the top 60 and top 100 prioritised questions identified earlier.

In conducting this exercise, two experienced researchers independently identified one of the eight concepts presented above in respect of each question. A considered discussion then took place between the two researchers and following that, agreement was reached on the concept considered most relevant for each question. Two additional categories were included.

- First, a category titled "Lead-in" was assigned to certain questions as they were not specific to any one of the concepts outlined but were required in order to determine whether a patient had experience of a particular event.
- Second, a category titled "Demographics" was included and this category took account of socio-demographic aspects such as ethnicity and gender.

Overview of prioritised questions by concept

An overview of these concepts as they relate to the top 60 prioritised questions is presented in Table 10 with the data presented in the Statistical Annex under Table A4 "Concepts of patient experience by question rank".

Table 10: Number of questions in top 60 according to concepts of patient experience

Concept	Number of questions
Demographics	1
Access to care	1
Lead-in	1
Emotional support	2
Involvement of family and friends	2
Co-ordination and integration of care across the health and social care system.	3
Respect for patient-centred values, preferences, and expressed needs	8
Overall	9
Physical comfort	8
Transition and continuity	9
Information, communication and education	16

Issues arising in respect of the conceptualisation of patient experience

The prioritised 60 questions include only a small number of some concept areas and a high number of others. There are a low number of questions relating to:

- Demographics   (n=1)
- Access to care   (n=1)
- Lead-in   (n=1)
- Emotional support   (n=2)
- Involvement of family and friends (n=2)

More than one-quarter of (n=16; 27%) of all the questions included in the top 60 relate to the concept "Information, communication and education" and a further seven questions are included in the top 100. These issues are now considered in greater detail.

Demographic questions

Table 11 shows that only one demographic question is included in the prioritised 60 questions. This may be problematic and additional demographic questions may be required. A second demographic question was ranked at number 60. No further demographic questions were included in the top 100 prioritised questions.

Some consideration may need to be given to the inclusion of an additional demographic question. It is also suggested that the question on gender be agreed with the CSO to ensure compatibility with the Irish context.

Table 11: Demographic questions in the top 60 identified by the Delphi panel

Rank	Question number	Question
56	Q178	What was your year of birth?
60=	Q177	Are you male or female?

Access to care

Only one question relating to access to care was included in the top 60 questions and, again, some consideration may need to be given to this. Questions relating to access prioritised in the top 100 questions are presented in Table 12. Seven questions are in the top 100.

Table 12: Questions on access to care in the top 100 identified by the Delphi panel

Rank	Question number	Question
23	Q85	Did you feel you had enough time to discuss your care and treatment with a doctor?
67	Q143	On the day you left hospital, was your discharge delayed for any reason?
74	Q136	Did you have enough time to discuss your operation or procedure with the consultant?
77	Q121	Were you told in advance when your tests, x-rays or scans were going to take place?
80	Q22	Following arrival at the hospital, how long did you wait before being admitted to a bed on a ward?
87	Q144	What was the MAIN reason for the delay? (Tick ONE box only)
91	Q123	Did a member of staff explain why the scheduled tests were not performed on time?
92	Q122	Were your scheduled tests, x-rays or scans performed on time?

Some consideration may need to be given to the inclusion of at least one question on this area being included in the top 60 questions to ensure access to care is adequately represented. The highest ranked question is Q143 *("On the day you left hospital, was your discharge delayed for any reason?")* and this was ranked at 67.

"Emotional support" and "Involvement of family and friends"

Some consideration may also need to be given to the concepts "Emotional support" and "Involvement of family and friends" as only two questions each were included in the overall top 60 questions.

Table 13: Questions in the top 100 linked with emotional support

Rank	Question number	Question

30	Q92	If you had any worries or fears about your condition or treatment, did a nurse discuss them with you?
46	Q84	If you had any worries or fears about your condition or treatment, did a doctor discuss them with you?
63	Q105	Did you find someone on the hospital staff to talk to about your worries and fears?
97	Q106	Do you feel you got enough emotional support from hospital staff during your stay?

As set out in Table 13, two additional questions are included in the top 100 questions and this may be sufficient to meet the requirement for taking account of the concept "Emotional support".

Similar to the concept "Emotional support", only two questions have been included in the top 60 in respect of the concept "Involvement of family and friends". Table 14 presents the highest ranked questions relating to "Involvement of family and friends".

Table 14: Questions in the top 100 linked with involvement of family and friends

Rank	Question number	Question
47	Q104	If your family or someone else close to you wanted to talk to a doctor, did they have enough opportunity to do so?
60=	Q142	Were your family or someone close to you given enough notice about your discharge?
89	Q59	Did you feel threatened during your stay in hospital by other patients or visitors?
101	Q69	Were you ever bothered by other patients' visitors?

As an additional question on the area "Involvement of family and friends" is included in the top 100 and a further question (Q69; rank 101) has been considered for inclusion in the top 60 under the theme "Visitors" in the section on patient journey. This may be sufficient to take account of the concept "Involvement of family and friends".

Information, communication and education

As noted earlier, more than a quarter of (n=16; 27%) of all the questions included in the top 60 relate to the concept "Information, communication and education". These questions are presented in Table 15 below.

Table 15: Rank of questions relating to "Information, communication and education"

Rank	Question number	Question
5	Q139	After the operation or procedure, did a member of staff explain how the operation or procedure had gone in a way you could understand?
8	Q62	Did the staff treating and examining you introduce themselves?
9	Q103	Was your diagnosis explained to you in a way that you could understand?

Rank	Question number	Question
13	Q124	Did a doctor or nurse explain the results of the tests in a way that you could understand?
20	Q83	When you had important questions to ask a doctor, did you get answers that you could understand?
21	Q132	Beforehand, did a member of staff explain the risks and benefits of the operation or procedure in a way you could understand?
22	Q134	Beforehand, did a member of staff answer your questions about the operation or procedure in a way you could understand?
25	Q135	Beforehand, were you told how you could expect to feel after you had the operation or procedure?
28	Q13	When you had important questions to ask doctors and nurses in the A&E Department, did you get answers that you could understand?
34	Q61	Did staff wear name badges?
37	Q91	When you had important questions to ask a nurse, did you get answers that you could understand?
38	Q16	While you were in the A&E Department, did a doctor or nurse explain your condition and treatment in a way you could understand?
41	Q96	If you ever needed to talk to a nurse, did you get the opportunity to do so?
50	Q101	How much information about your condition or treatment was given to you?
57	Q125	Before you received any treatments (e.g. an injection, dressing, physiotherapy) did a member of staff explain what would happen?
59	Q126	Before you received any treatments (e.g. an injection, dressing, physiotherapy) did a member of staff explain any risks and/or benefits in a way you could understand?

In the event that some questions need to be removed from the top 60, some consideration may be given to taking them from the 16 relating to the concept "Information, communication and education".

Lead-in questions

Some consideration will need to be given to lead-in questions. In respect of "Ambulance services", for example, it is clear that if questions are to be included about that service, a question about how individuals arrived at the hospital is also necessary. In addition, a lead-in question would be required for Q131 ("*During your stay in hospital, did you have an operation or procedure?*") which was ranked at 42 in Round 2 of the Delphi study. Table 16 presents all the lead-in questions with their ranks.

Table 16: Lead-in questions by rank in Round 2

Rank	Question number	Question
42	Q131	During your stay in hospital, did you have an operation or procedure?

65	Q2	Did you travel to the hospital by ambulance?
98	Q120	During your stay in hospital, did you have any tests, x-rays or scans other than blood or urine tests?
100	Q10	When you arrived at the hospital, did you go to the A&E Department (also known as the Emergency Department, Casualty, Medical or Surgical Admissions unit)?
155	Q41	When you were first admitted to a bed on a ward, did you share a sleeping area, for example a room or bay, with patients of the opposite sex?
169	Q40	While in hospital, did you ever stay in a critical care area (e.g. Intensive Care Unit, High Dependency Unit or Coronary Care Unit)?
180	Q137	Before the operation or procedure, were you given an anaesthetic or medication to put you to sleep or control your pain?
204	Q49	For most of your stay, what type of room or ward were you in?
209	Q107	Did you have to wear a hospital gown at any point during your stay in hospital?

When final decisions about each of the three areas (theme, conceptualisation of patient experience and HIQA standards), have been made, lead-in questions required will also need to be considered.

Summary issues arising around the concept of patient experience

In summary, some issues arise in respect of the conceptualisation of patient experience and there are considerable differences in the extent to which individual concepts are included. Areas where the Delphi panel selected only a small number of questions for inclusion in the top 60 include: "Demographics", "Access to care", "Lead-in" questions, "Emotional support" and "Involvement of family and friends".

Questions for consideration in respect of the theme "Involvement of family and friends" have been identified and Q69 ranked at 101 has been identified as potentially helpful for consideration as it also relates to the theme "Visitors". There are two additional questions in the top 100 questions relating to "Emotional support" and it is suggested that this may be sufficient.

In terms of access to care, Q37 ranked at 102 *("Was your admission date changed by the hospital?")* was identified as potentially helpful for inclusion in respect of "Admission to hospital and waiting list" and some consideration may also be given to it here.

While areas for consideration were identified under "Emotional support" and "Involvement of family and friends", there are additional questions in the top 100 and it is suggested that this may be sufficient to meet the requirements. The concept area "Information, communication and education" accounts for 27% of all questions included and, consequently, consideration may be given to questions in this area where some need to be removed.

7.3 HIQA National Standards for Safer Better Healthcare

While patient experience is a universal issue, it is important that questions included in the NPE questionnaire are relevant to the Irish context. In order to examine this issue, prioritised questions were mapped to the HIQA National Standards for Safer Better Healthcare. The National Standards for Safer Better Healthcare are framed around the following areas:

1. Person-centred care and support
2. Effective care and support
3. Safe care and support
4. Better health and wellbeing
5. Leadership, governance and management
6. Workforce
7. Use of resources
8. Use of information

Full question set in relation to the HIQA standards

Individual questions were mapped to specific standards and sub-standards by personnel at HIQA who have an in-depth knowledge of the standards and the concepts underpinning them. Some questions are applicable to more than one standard and this is identified where relevant. Some questions are not relevant to the HIQA standards (e.g. lead-in questions) and again this is highlighted. Figure 8 identifies the standards assigned to questions in the overall questionnaire set.

It is recognised that while some standards, for example, Standard 1, are very relevant to the measurement of patient experience, others cannot be directly related. This is highlighted below where Standard 4 and Standard 5 did not feature at all and where Standard 3 and Standard 6 were identified only a small number of times.

The text of key standards that were assigned to more than two questions in the overall question set is presented in Table 17.

Table 17: Standards assigned to more than two questions in the overall question set

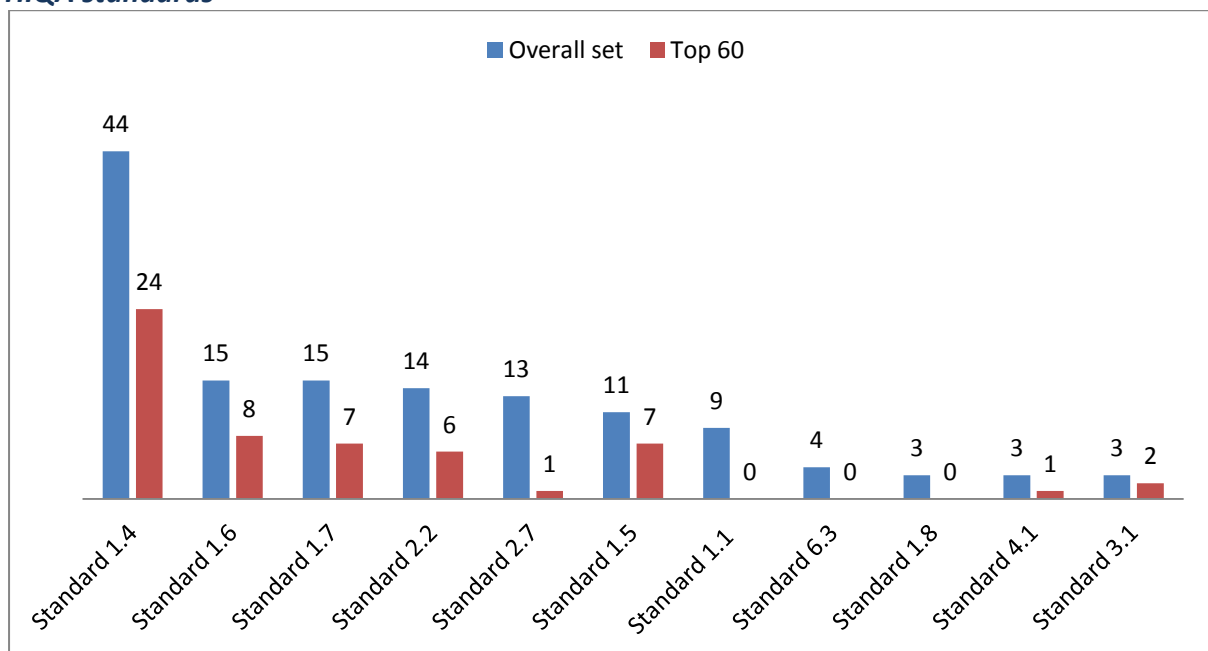| Title of standard	Standard
Standard 1.1	The planning, design and delivery of services are informed by service users' identified needs and preferences.
Standard 1.4	Service users are enabled to participate in making informed decisions about their care.
Standard 1.5	Service users' informed consent to care and treatment is obtained in accordance with legislation and best available evidence.
Standard 1.6	Service users' dignity, privacy and autonomy are respected and promoted.
Standard 1.7	Service providers promote a culture of kindness, consideration and respect.
Standard 2.2	Care is planned and delivered to meet the individual service user's initial and ongoing assessed healthcare needs, while taking account of the needs of other

	service users.
Standard 1.8	Service users' complaints and concerns are responded to promptly, openly and effectively with clear communication and support provided throughout this process.
Standard 2.7	Healthcare is provided in a physical environment which supports the delivery of high quality, safe, reliable care and protects the health and welfare of service users.
Standard 3.1	Service providers protect service users from the risk of harm associated with the design and delivery of healthcare services.
Standard 4.1	The health and wellbeing of service users are promoted, protected and improved.
Standard 6.3	Service providers ensure their workforce have the competencies required to deliver high quality, safe and reliable healthcare.

These standards are now considered in respect of the questions ranked in the top 60 questions.

Issues for consideration in respect of HIQA standards

There is considerable overlap between the HIQA standard assigned to the overall questionnaire set and the top 60 questions prioritised (Figure 8). Specifically, the highest number of questions in the overall set were identified as relevant to Standard 1.4 and questions related to this standard also accounted for the highest number included in the top 60 prioritised questions. This is also the case in respect of Standards 1.6 and 1.7 where the highest number of questions in the overall set assigned to this standard are also identified in the top 60 questions.

Figure 8: Comparison of full question library vs questions ranked in the top 60 according to HIQA standards

As some questions were assigned more than one HIQA standard and, as some were not assigned any standard, the total is not a reflection of the number of questions in the overall question library or in the top 60.

Some consideration is now given to two standard areas, Standard 1.1 and Standard 2.7, both of which featured more commonly in the overall questionnaire library compared with the top 60 questions ranked by the Delphi panel.

Standard 1.1

Standard 1.1 states that, *"The planning, design and delivery of services are informed by service users' identified needs and preferences".* This standard was assigned to nine questions in the overall question library but none were ranked in the top 60 questions by the Delphi panel. The ranking of questions according to Standard 1.1 are presented in Table 18.

Table 18: Rank of questions according to HIQA Standard 1.1

Round 2 Rank	Question number	Question
67	Q143	On the day you left hospital, was your discharge delayed for any reason?
102	Q27	Was your admission date changed by the hospital?
103	Q171	During your hospital stay, were you ever asked to give your views on the quality of your care?
109	Q165	After leaving hospital, do you think you received enough care and assistance from health or social services?
112	Q67	Were your visitors given enough information about visiting (e.g. visiting hours and rules)?
114	Q145	How long was the delay?
129	Q66	Were the visiting times convenient for your friends and family?
142	Q25	When you were told you would be going into hospital, were you given enough notice of your date of admission?
210	Q26	Were you given a choice of admission dates?

Some consideration may need to be given to the inclusion of a question relating to HIQA Standard 1.1 in the top 60 questions. The Delphi Panel ranked Q143 ("*On the day you left hospital, was your discharge delayed for any reason?"*) highest.

Standard 2.7

HIQA Standard 2.7 states that, *"Healthcare is provided in a physical environment which supports the delivery of high quality, safe, reliable care and protects the health and welfare of service users".* In the overall questionnaire library, 13 questions were assigned to this standard but only one in the top ranked 60 questions. The next highest ranked question was Q55 ("*Were you ever bothered by noise at night from hospital staff?*") and some consideration may need to be given to the inclusion of this question.

Table 19: Questions aligned with Standard 2.7

Round 2 Rank	Question number	Question
53	Q47	When you needed to use a toilet or bathroom, was there a suitable one located close by?
115	Q55	Were you ever bothered by noise at night from hospital staff?
126	Q54	Were you ever bothered by noise at night from other patients?
140	Q33	Was it easy to find your way to the ward?
141	Q148	Where did you spend your time waiting to be discharged from hospital?
156	Q53	Were you ever bothered by noise during the day from hospital staff?
159	Q52	Were you ever bothered by noise during the day from other patients?
185	Q35	Was it possible to find a convenient place to park in the hospital car park?
190	Q63	Did you find it easy to find your way around the hospital?
198	Q32	Once you arrived at the hospital, was it easy to find your way to the main reception?

As there are 24 questions in the top 60 relating to Standard 1.4, some consideration may be given to removing questions from this area if required.

Some consideration may also need to be given to the question area on "Open disclosure", identified in the Round 1of the Delphi study, and which was ranked at 75 in the second round.

Summary HIQA standards

In summary, this section has considered the alignment of the HIQA standards relevant to patient experience with the top 60 questions as ranked by the Delphi panel. In general, this alignment is satisfactory and most questions in both the overall questionnaire library and top ranked questions were related to person-centred care and support, and specifically, Standards 1.4, 1.6 and 1.7.

Two areas were identified as requiring further consideration and these were Standard 1.1 (relating to service users' needs and preferences) and Standard 2.7 (relating to the physical environment), neither of which featured strongly in the top 60 ranked questions. The case for including an additional question relating to Standard 1.1 was also considered.

7.4 Patient focus groups

The voice of the patient is crucial in considering the questions for inclusion the NPE questionnaire. In the second round survey, Delphi panel participants were provided with information on the views of the patient as indicated through the focus group discussions. The findings from the top 100 questions selected in the Delphi panel show a high level of consensus with the findings from the patient focus groups. Only four questions (one in the

top 60) were prioritised by the Delphi panel for inclusion (as either yes, it should be included or that it should be included but combined with another question) that had not also been identified by at least four out of six (67%) of the patient focus groups. These four questions are presented in Table 17.

Table 20: Questions selected by Delphi panel but not prioritised by patient focus groups

Round 2 Rank	Question	Question number	PFG% Yes/ Combo
13	Did a doctor or nurse explain the results of the tests in a way that you could understand?	Q124	33%
79	Was there one doctor in overall charge of your care?	Q82	50%
84	Beforehand, did a member of staff explain what would be done during the operation or procedure?	Q133	50%
97	Do you feel you got enough emotional support from hospital staff during your stay	Q106	33%

Recommendation to merge or combine questions from patient focus groups

Some consideration is now given to the recommendations made in focus group discussions to merge or combine some questions with others as a mechanism to reduce the number of questions overall. Further discussion and consideration of these recommendations may take place at a later time to inform future questionnaire developments.

Overall question library

In the overall question library of 189 questions, about half of all questions were recommended by at least one patient focus group to be combined with another question.

These recommendations were as follows:

- 45 questions were recommended to be combined with others by one focus group.
- 28 questions were recommended to be combined with others by two focus groups.
- Seven questions were recommended to be combined with others by three focus groups.
- One question was recommended to be combined with another by four focus groups.
- One question was recommended to be combined with another by five focus groups.
- Four questions were recommended to be combined with others by six focus groups.

Prioritised top 100 questions

In the 100 prioritised questions, seven questions were recommended by three or more patient focus groups to be combined or merged with other questions (Table 21). Consideration is now given to these questions and to the commentary provided through the focus group discussions.

Table 21: Prioritised questions by rank identified by patient focus groups to be combined

Round 2 Rank	Round 2 Question	Q#	No. patient focus groups
38	While you were in the A&E Department, did a doctor or nurse explain your condition and treatment in a way you could understand?	Q16	3
62	In your opinion, how clean was the A&E Department?	Q19	5
55	Were you ever unable to eat during mealtimes (e.g. because you were away from the ward, recovery from surgery etc)?	Q78	3
51	Were you offered a replacement meal at another time?	Q79	3
46	If you had any worries or fears about your condition or treatment, did a doctor discuss them with you?	Q84	3
37	When you had important questions to ask a nurse, did you get answers that you could understand?	Q91	3
30	If you had any worries or fears about your condition or treatment, did a nurse discuss them with you?	Q92	3

Comments and considerations relating to Q16

The commentary relating to this question suggested that the question could be combined or merged with either Question 11 or Question 13. Q11 was not included in the top 100. Q13, however, was ranked at number 28 in the overall 100 questions. Question 16 relates to the patient's understanding of the information about their condition and treatment, while Q13 relates to more general understandings of questions.

In the context of the conceptualisation of patient experience, where there are 16 questions relating to "Information, communication and education", some consideration could be given to the overlap between both these questions and one could potentially be removed. Consideration could also be given to removing Question 16.

Comments and considerations relating to Q19

Q19 refers to the cleanliness of the A&E Department and commentary suggested that this question could be merged with Q20 which specifically asked about the cleanliness of the toilet facilities. The commentary noted that although it was agreed by the participants that Q19 and Q20 were important questions to ask, it was suggested that Q19 and Q20 could be combined to make one question. One focus group noted that question Q20 was more important than Q19 while another suggested Q18 could be combined with Q19. It was also highlighted that if a patient is ill, they might not know whether the facilities are clean and it was noted with a large influx of patients, staff and visitors to the A&E Department every day it is not always going to be 'sparkly clean'. Neither Q18 nor Q20 are included in the top 100 questions.

While it may be possible to re-word this question to include both the general cleanliness of the A&E Department and the toilet facilities within it, the question would lose its current international comparability.

Comments and considerations relating to Q78 and Q79

Questions 78 and 79 refer to access to food, with Question 79 being a supplementary question to Question 78. Three focus groups indicated that both these questions could be merged and the commentary mainly noted the importance of this area. One focus group, however, felt that Question 78 could be omitted from the survey.

Both questions 78 and 79 are included in the top 60 but it is not clear how these questions could be merged or combined.

Comments and considerations relating to Q84

The participants suggested that Q84, Q85 and Q86 could be combined to make one question. Question 84 refers to discussing worries and fears with a doctor, Question 85 refers to having enough time to discuss issues with the doctor and Question 86 relates to having confidence and trust in the doctor. The three questions are as follows:

- If you had any worries or fears about your condition or treatment, did a doctor discuss them with you? (Q84)
- Did you feel you had enough time to discuss your care and treatment with a doctor? (Q85)
- Did you have confidence and trust in the doctors treating you? (Q86)

Commentary mainly focused on Q86. Some participants suggested taking out the question from the survey altogether as they were unsure about the use of the word 'trust', while other participants at the same focus group discussed possibly rewording the question from "*Did you have confidence and trust*..." to, for example, "*How did you feel about the doctors treating you*...?" The rationale behind the rewording was that a patient may have a personality clash or another personal issue with the doctor and nurses, therefore, impacting on their trust they place in the professionals.

Of the three questions (Q84-Q86), Question 84 and Question 85 are prioritised in the top 100 and this may be sufficient.

Comments and considerations relating to Q91 and Q92

These questions refer to nurses' engagement with patients and similar type issues arise as those relating to doctors. No commentary was presented with these two questions although it was highlighted by one focus group that both questions were very important and by others that these could be combined with each other. One patient focus group suggested a merging of three questions (Q91, Q92, and Q93) could be considered. Q91 refers to "important questions" being answered by the nurses in a way the patient understands and

links in to the concept of "Information, communication and education". Q92 relates to worries or fears and is more closely connected to the concept of "Emotional support".

Given these different concepts under examination, it is suggested that as both Q91 and Q92 are included in the overall prioritised set, no change is required.

Patient focus groups: Summary of issues arising

In summary, consideration has been given in this section to two issues relating to the patient focus groups. First, the extent to which there was consensus between the final 100 questions ranked by the Delphi panel and the views of the patients through the focus groups was considered. The findings show a high level of consensus between both with only one question included in the top 60 selected by the Delphi panel and three in the top 100 that had not been selected by the patients' focus groups.

A second issue considered in this section related to the recommendations by the focus groups that some questions could be merged or combined with each other. In the final 100 Delphi panel-prioritised questions, seven questions were identified by patients as having the potential to be merged or combined. Each of these questions have been considered and a recommendation for the removal of Q16 ("*While you were in the A&E Department, did a doctor or nurse explain your condition and treatment in a way you could understand?*") due to its similarity with Q13 has been suggested.

7.5 Summary

This section has considered the top ranked question across four areas. These areas are: the patient journey through the health care services; the conceptualisation of patient experience; the relevance of the prioritised questions to the Irish context through a consideration of HIQA National Standards for Safer Better Healthcare; and, finally, the views of the patients as expressed through the patient focus groups which took place prior to the Delphi study.

The findings show that, with a small number of exceptions, the prioritised set of questions are satisfactory in each of these four areas. A small number of areas for consideration are highlighted where questions relating to the themes, patient experience concepts and alignment with HIQA standards are not fully comprehensive. Potential solutions to these have been presented and these are based on the highest ranking question selected by the Delphi panel that meets the criteria required. In addition, consideration has been given to the similarities between the findings from patient focus groups and those of the Delphi panel and the extensive overlap is highlighted. Recommendations by the patient focus groups to merge or combine specific questions have also been considered in this section and with the exception of one question, no changes are suggested.

8.0 Conclusion

This report provides a detailed account of the Delphi process adopted in the identification of 60 key questions for inclusion in the National Patient Experience (NPE) questionnaire and an additional 40 questions ranked for inclusion if required. These questions were drawn from a library of 189 questions provided by Picker Institute Europe. Following this process, consideration will be given to these questions by the Picker Institute Europe to ensure the final set of questions reflect the maximum gain for the Irish health services. The study was commissioned by the National Patient Experience Programme and overseen by an Advisory and Delivery group.

A two-round Delphi methodology was adopted for the implementation of the study. This was particularly useful in achieving consensus across a variety of different stakeholders who are not ordinarily in direct communication with each other. The panel of expertise was developed using a combination of a purposive snowball sampling methodology and literature search. In total, 58 participants from a variety of stakeholder groups, including policy-makers, managers, clinicians, patients and data research experts, consented to take part. A response rate of 97% (n=58) was achieved in the first round and 80% (n=48) in the second round.

The first round questionnaire focused on identifying those questions considered to be the most important to include in the NPE questionnaire. A five-point categorical scale was used with the response categories: 'definitely yes', 'probably yes', 'maybe yes / maybe no', 'probably no', and 'definitely no'. The questionnaire was pre-tested (n=2) and piloted (n=3) prior to implementation. Analysis of the data took place using descriptive statistics.

Findings

A cut-off point of 75% was used in the first round to identify priorities; that is, where 75% or more of the participants on the Delphi panel agreed a question should probably or definitely be included in the NPE questionnaire, it was identified as a priority. Using this approach, 105 questions were identified as priorities. Qualitative analysis took place on information provided by participants in respect of the rationale for why individual questions should not be prioritised and this information was made available in the second round.

Participants were also asked if they thought there were any additional areas that had not been included in the first round. A total of 33 question areas were identified and these ranged from "family and carers" to "patient characteristics" to "services and supports". Questions about each of these areas were included in the second round Delphi and participants were asked to indicate whether they should be included in the NPE questionnaire.

The integration of data from the first round study was compared with the findings from the patient and data user focus groups and this showed a high level of consensus. Out of the overall question library of 189 questions, there were 64 questions that were common to all three groups.

The second round questionnaire provided information on the findings from the focus groups in respect of each individual question and participants were asked to take this information into account in their deliberations. A sliding scale from 0-100 was used in the second round to rate questions to be included in the NPE questionnaire. The availability of continuous data facilitated the use of measures of central tendency (the mean) and dispersion (standard deviation).

At the end of the second round, the top 100 questions were identified using a cut-off point of a mean of 75 or higher. Within this, 35 questions had a mean of 90 or higher suggesting a very high level of consensus around these questions.

Issues considered

The top 60 prioritised questions from the second round were assessed against the thematic main areas outlined in Picker Institute Europe library of questions to determine comprehensiveness across all thematic areas. Three areas, "the Ambulance service", "Waiting lists or planned admissions" and the sub-theme of "Visitors" under "Hospital and wards", did not have any questions in the top 60 prioritised. In the top 100 prioritised questions, the "Ambulance service" was identified as having three questions, while "Waiting lists or planned admissions" and the "Visitors" sub-theme were not identified as having any. In contrast, the theme "Leaving hospital" was identified as having 13 prioritised questions in the top 60. Suggestions about the inclusion of a small number of different questions were made to accommodate these differences.

Some consideration was also given to the concept of patient experience and, similar to the themes identified in respect of the thematic areas, some variation was identified in the extent to which individual areas were prioritised. While 16 questions (27%) relating to the concept "Information, communication and education" were included in the top 60, areas such as "Demographics", "Access to care", "Emotional support", "Involvement of family and friends" and "Lead-in" questions had only one or two questions on each one. Some consideration was given to how these deficits could be addressed and suggestions for changes identified.

In order to ensure the prioritised questions aligned with the Irish context, benchmarking took place against the relevant area under the HIQA standards. Again, some issues were identified and some standards (e.g. Standard 1.1 "*The planning, design and delivery of services are informed by service users' identified needs and preferences*") did not have any prioritised questions in the top 60. A similar situation applied in respect of Standard 2.7

("*Healthcare is provided in a physical environment which supports the delivery of high quality, safe, reliable care and protects the health and welfare of service users*") where only one question was prioritised, despite 13 questions being available in the library of 189 questions. Twenty-four questions relating to Standard 1.4 were identified in the top 60 and this accounted for 40% of all questions prioritised. Standard 1.4 states that, "*Service users are enabled to participate in making informed decisions about their care*".

The final area of deliberation in respect of the prioritised questions related to the recommendations by patient focus groups to combine or merge some questions. While 86 questions were identified by between one and six focus groups to be combined with others, only seven of those questions were included in the top 100 prioritised. Each of these questions were considered in detail.

In conclusion, the findings from the Delphi study showed considerable consensus across the panel and also with the findings from patient and data user focus groups. Some issues arose in respect of the prioritised questions and in order to take account of these issues, a small number of changes were suggested. The suggestions made were based on the highest ranked questions selected by the Delphi panel that met the requirements outlined.

The next section presents the top 60 and additional 40 questions prioritised by the Delphi panel.

9.0 Questions prioritised by the Delphi panel

Top 60 questions selected by the Delphi panel

Rank	Question number	Questions
1	Q110	Were you given enough privacy when being examined or treated?
2	Q196	Was there anything particularly good about your hospital care?
3	Q21	Overall, did you feel you were treated with respect and dignity while you were in the A&E Department?
4	Q109	Were you given enough privacy when discussing your condition or treatment?
5	Q139	After the operation or procedure, did a member of staff explain how the operation or procedure had gone in a way you could understand?
6	Q169	Overall, were you treated with kindness and understanding while you were in the hospital?
7	Q168	Overall, did you feel you were treated with respect and dignity while you were in the hospital?
8	Q62	Did the staff treating and examining you introduce themselves?
9	Q103	Was your diagnosis explained to you in a way that you could understand?
10	Q140	Did you feel you were involved in decisions about your discharge from hospital?
11	Q197	Was there anything that could be improved?
12	Q12	Were you given enough privacy when being examined or treated in the A&E Department?
13	Q124	Did a doctor or nurse explain the results of the tests in a way that you could understand?
14	Q159	Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?
15	Q149	Before you left hospital, did the doctors and nurses spend enough time explaining about your health and care after you arrive home?
16	Q80	Did you get enough help from staff to eat your meals?
17	Q100	Were you involved as much as you wanted to be in decisions about your care and treatment?
18	Q151	Did a member of staff explain the purpose of the medicines you were to take at home in a way you could understand?
19	Q117	Do you think the hospital staff did everything they could to help control your pain?
20	Q83	When you had important questions to ask a doctor, did you get answers that you could understand?
21	Q132	Beforehand, did a member of staff explain the risks and benefits of the operation or procedure in a way you could understand?
22	Q134	Beforehand, did a member of staff answer your questions about the operation or procedure in a way you could understand?
23	Q85	Did you feel you had enough time to discuss your care and treatment with a doctor?
24	Q198	Any other comments?
25	Q135	Beforehand, were you told how you could expect to feel after you had the operation or procedure?
26	Q157	Did the doctors or nurses give your family or someone close to you all the

		information they needed to help care for you?
27	Q70	How would you rate the hospital food?
28	Q13	When you had important questions to ask doctors and nurses in the A&E Department, did you get answers that you could understand?
29	Q56	In your opinion, how clean was the hospital room or ward that you were in?
30	Q92	If you had any worries or fears about your condition or treatment, did a nurse discuss them with you?
31	Q51	Were you given enough privacy while you were on the ward?
32	Q48	When you needed help from staff getting to the bathroom or toilet, did you get it in time?
33	Q152	Did a member of staff tell you about medication side effects to watch for when you went home?
34	Q61	Did staff wear name badges?
35	Q156	Did hospital staff take your family or home situation into account when planning your discharge?
36	Q127	Did you feel you could refuse any treatment that you did not agree with or did not want?
37	Q91	When you had important questions to ask a nurse, did you get answers that you could understand?
38	Q16	While you were in the A&E Department, did a doctor or nurse explain your condition and treatment in a way you could understand?
39	Q97	How would you rate the courtesy of your nurses?
40	Q77	Was the hospital food suitable for your dietary needs?
41	Q96	If you ever needed to talk to a nurse, did you get the opportunity to do so?
42	Q131	During your stay in hospital, did you have an operation or procedure?
43	Q57	How clean were the toilets and bathrooms that you used in hospital?
44	Q150	Before you left hospital, were you given any written or printed information about what you should or should not do after leaving hospital?
45	Q89	How would you rate the courtesy of your doctors?
46	Q84	If you had any worries or fears about your condition or treatment, did a doctor discuss them with you?
47	Q104	If your family or someone else close to you wanted to talk to a doctor, did they have enough opportunity to do so?
48	Q39	How would you rate the courtesy of the staff who admitted you?
49	Q155	Did a member of staff tell you about any danger signals you should watch for after you went home?
50	Q101	How much information about your condition or treatment was given to you?
51	Q79	Were you offered a replacement meal at another time?
52	Q153	Were you told how to take your medication in a way you could understand?
53	Q47	When you needed to use a toilet or bathroom, was there a suitable one located close by?
54	Q141	Were you given enough notice about when you were going to be discharged?
55	Q78	Were you ever unable to eat during mealtimes (e.g. because you were away from the ward, recovery from surgery etc)?
56	Q178	What was your year of birth?
57	Q125	Before you received any treatments (e.g. an injection, dressing, physiotherapy) did a member of staff explain what would happen?
58	Q162	Do you feel that you received enough information from the hospital on how to manage your condition after your discharge?
59	Q126	Before you received any treatments (e.g. an injection, dressing, physiotherapy) did a member of staff explain any risks and/or benefits in a way you could understand?
60=	Q142	Were your family or someone close to you given enough notice about your discharge?
60=	Q177	Are you male or female?

Additional 40 questions selected by the Delphi panel

Rank	Question number	Question
61	Q74	Were you offered a choice of food?
62	Q19	In your opinion, how clean was the A&E Department?
63	Q105	Did you find someone on the hospital staff to talk to about your worries and fears?
64	Q1	Was your most recent hospital stay planned in advance or an emergency?
65	Q161	Did hospital staff discuss with you whether you may need any further health or social care services after leaving hospital? (e.g. services from a GP, physiotherapist or community nurse, or assistance from social services or the voluntary sector).
66	Q102	While you were in hospital, were you told your diagnosis (explanation of what was wrong with you)?
67	Q143	On the day you left hospital, was your discharge delayed for any reason?
68=	Q86	Did you have confidence and trust in the doctors treating you?
68=	Q93	Did you have confidence and trust in the nurses treating you?
69	Q170	Overall... (Please rate)
70	Q154	Were you given clear written or printed information about your medicines?
71	Q60	Did you have somewhere to keep your personal belongings whilst on the ward?
72	Q158	Did hospital staff tell you when you could resume your usual activities, such as when to go back to work or drive a car?
73	Q72	Was there healthy food on the hospital menu?
74	Q136	Did you have enough time to discuss your operation or procedure with the consultant?
75	New question	Question on whether the patient was informed in a timely manner if things went wrong (in line with open disclosure)
76	Q160	Did hospital staff discuss with you whether you would need any additional equipment in your home, or any adaptations made to your home, after leaving hospital?
77	Q121	Were you told in advance when your tests, x-rays or scans were going to take place? [Prioritised by all groups]
78	Q173	Did you want to complain about the care you received in hospital?
79	Q82	Was there one doctor in overall charge of your care?
80	Q22	Following arrival at the hospital, how long did you wait before being admitted to a bed on a ward?
81	Q76	Do you have any special dietary requirements (e.g. vegetarian, diabetic, food allergies)?
82	Q11	While you were in the A&E Department, how much information about your condition or treatment was given to you?
83	Q138	Before the operation or procedure, did the anaesthetist or another member of staff explain how he or she would put you to sleep or control your pain in a way you could understand?
84	Q133	Beforehand, did a member of staff explain what would be done during the operation or procedure?
85	Q172	Did you see, or were you given, any information explaining how to complain to the hospital about the care you received?
86	Q81	How would you rate the courtesy of the catering staff?
87	Q144	What was the MAIN reason for the delay? (Tick ONE box only)
88	Q14	While you were in the A&E Department, did you have confidence and trust in the doctors and nurses examining and treating you?
89	Q59	Did you feel threatened during your stay in hospital by other patients or visitors?

90	Q95	In your opinion, were there enough nurses on duty to care for you in hospital?
91	Q123	Did a member of staff explain why the scheduled tests were not performed on time?
92	Q122	Were your scheduled tests, x-rays or scans performed on time? [Prioritised by both DP and Pt groups]
93	Q75	Did you get the food you ordered?
94	Q6	Overall, did the ambulance crew treat you with respect and dignity?
95	Q98	In your opinion, did the nurses who treated you know enough about your condition or treatment?
96	Q9	Overall, how would you rate the care you received from the ambulance service?
97	Q106	Do you feel you got enough emotional support from hospital staff during your stay?
98	Q120	During your stay in hospital, did you have any tests, x-rays or scans other than blood or urine tests?

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